

DOCTOR OF PHILOSOPHY

How is life experienced by teenagers with dyspraxia? An interpretative phenomenological analysis

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How is life experienced by teenagers with dyspraxia? An interpretative phenomenological analysis.

Sarah Payne

PhD

June 2015



How is life experienced by teenagers with dyspraxia? An interpretative phenomenological analysis.

Volume 2

Sarah Payne

June 2015

***A thesis submitted in partial fulfilment of the University's requirements for
the Degree of Doctor of Philosophy***

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Declaration

I declare that the main text of this thesis is entirely my own work. This work has not been previously submitted wholly or in part for any academic award or qualification other than that for which it is now submitted.

Signature

Date

Sarah J Payne

June 2015

Abstract

Background

Dyspraxia, a form of developmental coordination disorder (DCD), is one of the most common disorders of childhood (Wann 2007). However, while there is increasing evidence that in many cases childhood motor difficulties persist into adulthood (Kirby et al 2013) little is known about the impact of the condition during adolescence. Moreover, existing research reflects the interests and concerns of professionals and parents rather than the perspectives of teenagers themselves.

Methodology

The study was guided by the philosophical principles of interpretative phenomenological analysis (IPA). A Research Reference Group of older teenagers and young adults with dyspraxia was involved in the study design and analysis of findings. Sixteen interviews were carried out with teenagers aged 13-15 years over a two year period. Participants' accounts were subjected to a systematic process of ideographic, inductive and interpretative analysis.

Findings

Five themes that represent the lived experience of dyspraxia during adolescence emerged. These were: *“Doing everything the hard way”*; *“I didn’t want to be seen as someone different”*; *“I’m an intelligent person but I can’t even write. It’s making me fill up”*; right help, right time; and making sense of the diagnosis. In accordance with the philosophical principles of IPA the findings prioritise the voice of the participants, and my influence as the researcher and insights offered by the Reference Group on the interpretation of findings are acknowledged. Evidence built through the process of interpretative analysis is drawn together into a conceptual framework. This is presented as a novel means of demonstrating the complex interaction of personal and environmental factors that influence the lived experience of DCD/dyspraxia during adolescence and their impact on teenagers' sense of identity, agency, ambition and emotional resilience. The thesis concludes by summarising the new understandings about DCD/dyspraxia that the study brought forth, identifying how these might help parents, professionals, support organisations including the Dyspraxia Foundation and researchers to improve outcomes for teenagers living with DCD/dyspraxia in the future.

Chapter 1

Background to the study

Chapter 1: Background to the study

Introduction

This thesis presents a qualitative study to explore teenagers' experience of living with dyspraxia. The study adopted an interpretative phenomenological approach (Smith, Flowers and Larkin 2009) as a means of advancing knowledge of how life is experienced by teenagers with dyspraxia from their own contemporaneous perspective. The evidence built throughout this study is drawn together into a conceptual framework which is offered as means of helping young people with dyspraxia, parents, occupational therapists, other health professionals, teachers and organisations such as the Dyspraxia Foundation to understand the factors that influence teenagers' lives. A practice model for occupational therapists based on the study findings is proposed.

This opening chapter sets the scene by providing a background and rationale for the research. It includes a discussion about terminology, prevalence and aetiology and describes the contextual factors that influence contemporary research and practice with teenagers who have dyspraxia. A rationale for the involvement of a Research Reference Group and the use of interpretative phenomenological analysis as the research method is presented and the research aim and objectives are stated. This chapter concludes with a synopsis of each chapter.

Background

I am an occupational therapist working in clinical practice with young people whose occupational performance is affected by a range of personal, environmental and task-related factors. Around half of those referred to my service have unexplained motor coordination difficulties, many of whom receive a diagnosis of dyspraxia or developmental coordination disorder (DCD). I first encountered the term 'dyspraxia' whilst working as a member of a child development team in the early 1990's and in 1999 I presented a poster at the National Association of Paediatric Occupational Therapists conference on the role of the occupational therapist with teenagers who have dyspraxia, recognising even at this time that this was a neglected population for whom occupational therapy could make a difference. My interest in the area developed when I carried out a series of focus groups with young people aged 9-13 years to produce a "Handbook for Children with Coordination Difficulties" written with and for young people with dyspraxia in 2006. Shortly afterwards I produced a short film in which three teenagers with the condition described their experience of secondary school; this has proved to be a powerful training tool in my clinical practice to raise awareness of dyspraxia amongst teachers, parents and professionals. I have also been fortunate to meet many children and adults living with the condition through my long-standing association with the Dyspraxia Foundation; this has furthered my understanding of dyspraxia as a life-long condition. Hearing the stories of

teenagers and adults has enhanced my clinical practice by giving me greater insight into the everyday challenges that people with dyspraxia face. My motivation for this research was to give people with dyspraxia a voice in a discourse dominated by professionals and academics; to explicate the experience of teenagers living with dyspraxia to inform the practice of professionals and organisations that support them; and to provide a direction for future research.

In the follow section I discuss the terminology used to describe people with motor coordination difficulties and provide some background information about DCD/dyspraxia, including a summary of current thinking about the prevalence and aetiology of the condition.

Definition of terms

Clinicians and researchers have long been aware that there are a group of children whose motor difficulties affect their performance of everyday activities but for which no neurological explanation exists (Chambers, Sugden and Sinani 2005, Dewey and Wilson 2001). The terminology used to describe this group of children has been the subject of considerable debate for many years (Addy and Dixon 1999, Dewey and Wilson 2001, Peters, Barnett and Henderson 2001). Terms used include clumsy child syndrome (Dare and Gordon 1970, Gubbay 1975, Hall 1988); developmental dyspraxia (Ayres 1994, Portwood 1996); and perceptuo-motor dysfunction (Laslow, Bairstow and Bartrip 1988). The terminology used is influenced by an individual's disciplinary background (Magalhães, Missiuna and Wong 2006) and beliefs about the underlying cause of the condition (Dewey and Wilson 2001). Variations in terminology however make it difficult to compare studies and draw conclusions about the effectiveness of interventions. To address the problem of inconsistency an International Consensus Conference on Children and Clumsiness in 1994 agreed that in research and clinical practice the term 'developmental coordination disorder' (DCD) should be used (Polatajko, Fox and Missiuna 1995). This term was adopted by The American Psychiatric Association which has included clear criteria for the diagnosis of DCD in the Diagnostic and Statistical Manual for Mental Disorders since 1987; these criteria were recently revised and updated in the newest version of the manual (American Psychiatric Association 2013) (Figure 1).

In the United Kingdom the term 'dyspraxia' continues to be widely used within education (Jones 2005, Portwood 1996, Portwood 2000) while the national charity supporting people affected by the condition is known as the Dyspraxia Foundation. It has been argued that the term dyspraxia is confusing because its use varies between individuals and disciplines (Kirby, Davies and Bryant 2005) and there is a lack of consensus about what the term means (Gibbs, Appleton and Appleton 2007, Hill and Barnett 2011). However, many parents (Miyahara and Baxter 2011, Novak et al. 2012) and people living with the condition prefer to use the term dyspraxia when talking about their diagnosis

(Biggs 2005, Lingam et al. 2014) as it reflects their experience that difficulties are not just limited to poor motor coordination (Novak et al. 2012). The Dyspraxia Foundation definition of dyspraxia is given in Figure 2.

Figure 1: Criteria for the diagnosis of DCD, American Psychiatric Association, 2013

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In this thesis I have chosen to use the expression 'DCD/dyspraxia' when referring to the diagnosis. While this terminology risks drawing criticism for implying uncertainty (Magalhães, Missiuna and Wong 2006) it acknowledges the international agreement to use the term DCD whilst reflecting participants' and Reference Group members' preference for the term 'dyspraxia'. When referring to the literature or participants' accounts however, terminology used by the author or participant is respected.

Figure 2: Definition of dyspraxia, Dyspraxia Foundation, 2013

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Prevalence, impact and aetiology of DCD/dyspraxia

DCD is a disorder characterized by deficits in motor coordination which significantly interfere with an individual's participation in day-to-day activities at home, at school and/or in other settings (American Psychiatric Association 2013). Prevalence rates are reported at between 1.7% - 6% of school-aged children (American Psychiatric Association 2013, Lingam et al. 2009) making DCD one of the most common disorders of childhood (Wann 2007). The condition affects more boys than girls, although gender ratios vary according to the population studied. A UK population-based study by Lingam et al. (2009) reported a gender ratio of 1.7:1 boys to girls. DCD/dyspraxia can have a significant impact across a variety of functional domains. Recently the International Classification of Functioning, Disability and Health (ICF) has been used as a framework to demonstrate the impact of the condition on body functions, activities and participation (Ferguson et al. 2014, Watter et al. 2008, Zwicker et al. 2012).

Diagnosis of DCD/dyspraxia cannot be made by an assessment of motor coordination alone; there also needs to be evidence of the negative impact of motor difficulties on everyday activities (American Psychiatric Association 2013). In clinical practice such evidence is typically gathered from parents, teachers and young people through questionnaire, interview and observation (Blank et al. 2012). A systematic review of the literature by Magalhaes et al (2011) however, concluded that

research about activity limitations and participation restrictions of children with DCD was limited in both scope and volume. Functional issues cited most frequently in the literature were poor handwriting and difficulty playing ball games, getting dressed and participating in organised sports. Another systematic review by Zwicker et al (2012) demonstrated the impact of DCD/dyspraxia on psychosocial function, concluding that young people with DCD experienced significantly more symptoms of anxiety and depression and were at greater risk of lower self-esteem and social difficulties than their well-coordinated peers; they therefore had an overall lower quality of life.

There is a strong overlap between DCD/dyspraxia and other developmental disorders. The coexistence of DCD and attention deficit hyperactivity disorder (ADHD) is well-reported and motor coordination difficulties are estimated to be present in around 50% of children with ADHD (Dewey et al. 2002). A similar level of co-occurrence occurs with reading difficulties (Kaplan et al. 1998) and specific language impairment (Hill 2001). Research indicates that the co-existence of such disorders has a significant negative impact on academic, social and behavioural outcomes (Rasmussen and Gillberg 2000).

Children with DCD/dyspraxia form a heterogeneous group, reflecting uncertainty about causes of the condition and the influence of environmental factors on the development and impact of motor impairment. Some researchers believe there is a neurological basis to the disorder relating to dysfunction in particular brain areas (Ferguson et al. 2014). Recent studies using functional Magnetic Resonance Imaging have provided some support for this theory by showing that young people with DCD demonstrate different patterns of brain activation compared to typically developing children (Zwicker et al. 2010). An alternative explanation is that DCD/dyspraxia is the result of delayed maturation of the nervous system and insufficient stimulation of the developing brain (Zwicker, Missiuna and Boyd 2009). Studies suggest that there may also be a genetic component to the condition (Sugden, Kirby and Dunford 2008). DCD/dyspraxia has been associated with lower socioeconomic backgrounds, low birth weight (below 2500g) and birth before 37 weeks gestation (Lingam et al. 2009). Despite early thoughts that DCD/dyspraxia (or 'clumsiness') was caused by neurological immaturity and was something that children would outgrow (Hall 1988) longitudinal studies have indicated that for the majority of people this is not the case (Gillberg, Gillberg and Groth 1989, Losse et al. 1991). Furthermore, there are a small but growing number of studies exploring the experience of DCD/dyspraxia in adulthood demonstrating that for many people DCD/dyspraxia is a life-long condition (Cantell, Smyth and Ahonen 2003, Fitzpatrick and Watkinson 2003, Kirby et al. 2013).

In summary, DCD/dyspraxia is a common childhood condition affecting around 5% of school aged children. It is a complex disorder characterised by movement difficulties that interfere with a person's activities of daily living. There is growing evidence in UK and international literature that movement difficulties often persist beyond childhood and may have serious negative consequences for a person's academic achievement, physical health and their social, emotional and economic well-being. Teenagers with DCD/dyspraxia are however under-represented in the literature and little is known about how the condition affects individuals from their own perspective. I argue that as a relatively common condition with potential long term adverse consequences, there is a need for further research to develop understanding of the impact of DCD/dyspraxia during adolescence. This is important as adolescence is a time of developmental change representing the transition from childhood to adulthood. Furthermore, qualitative research examining the lived experience of DCD/dyspraxia is limited, suggesting the need for additional research exploring a more personalised perspective than a quantitative approach might achieve. New understandings derived from such research will enable parents, health professionals, teachers and organisations to develop practice and support to improve outcomes for young people living with the condition. Before examining the context in which this thesis is presented I will briefly define what I understand by the term 'adolescence' and the significant developmental changes that occur at this time.

Adolescence

Adolescence is defined by the World Health Organisation as ages 10-19 years (Hagell, Coleman and Brooks 2013). It is an important life phase, typically understood to represent the period between the onset of puberty and the achievement of relative self-sufficiency (Blakemore and Millks 2013). The Association for Young People's Health (Hagell, Coleman and Brooks 2013) identifies three domains of adolescent development: physical, cognitive and emotional. Physical changes include the onset of puberty and the adolescent growth spurt, both of which may affect motor coordination (MacLeod, Bruce and Bell 1999, Visser, Geuze and Kalverboer 1998). Research reveals adolescence to be a time of significant cognitive development associated with changes in the anatomy and functioning of the brain leading to a brain that is more efficient and adapted to the surrounding environment (Coleman 2011). Cognitive processes including executive functions such as memory, problem-solving abilities and attention shifting develop at this time (Blakemore and Choudhry 2006). Adolescence is also a significant time for emotional development including the development of identity and self-concept (Sokol 2009). Social influences have a powerful impact on adolescents as they become increasingly aware of the attitudes, behaviours and judgements of their peers and start to define themselves by group membership and peer associations. While families remain important, new and significant relationships are formed at this time.

Adolescence is associated with cultural expectations of increased independence and autonomy. At school students are expected to assume greater responsibility for their daily lives and learning (Zimmerman and Cleary 2006). They are no longer under the control of one teacher and are expected to manage different teaching styles, to complete work outside the classroom and to cope with increased difficulty and pace of work. There may be cultural expectations that an individual will manage new challenges such as finding employment, learning to drive and taking responsibility for their personal finances.

In summary, adolescence is a time of significant biological, emotional and social change presenting additional challenges for young people already disadvantaged by poor motor coordination. The majority of previous research has focused on younger children with DCD/dyspraxia because this is when motor deficits are first noticed (Clark and Whitall 2011). However there is a need to better understand the impact of motor difficulties on social and emotional function during the important adolescent life phase.

The study context

The previous section provided some background about the prevalence and presentation of DCD/dyspraxia and justified the need for further research into this common lifelong condition. The following section describes the clinical, research, educational, occupational therapy and social contexts in which the research took place and is presented.

The context for this study has changed and evolved significantly since I began my research in 2008. Knowledge and practice with young people with DCD/dyspraxia has been influenced the publication of new research. There is also increased public awareness of DCD/dyspraxia and growing recognition of DCD/dyspraxia as a life-long condition. The publication of internationally-recognised guidelines for the description, definition, diagnosis and treatment of children with DCD by the European Academy of Childhood Disability at the end of 2011 (Blank et al. 2012) and the revised criteria for the diagnosis of DCD published by the American Psychiatric Association in 2013 were particularly significant events, the implications of which are discussed in this section. I also describe the research, political, economic and educational contexts in which this study is presented. In addition I will explore the occupational therapy environment and the changing social context in which parents and people affected by DCD/dyspraxia seek and influence service delivery.

DCD is formally recognised by international organisations including the American Psychiatric Association and the World Health Organisation. It is listed as a motor disorder in the Diagnostic and Statistical Manual for Mental Disorders and criteria for diagnosis were updated in the most recent revision of the manual, DSM-V (American Psychiatric Association 2013). Developmental coordination

disorder is listed as a specific developmental disorder of motor function (SDDMF) by the World Health Organisation (1992). The DSM criteria are however, more commonly used in research and clinical practice in the UK and elsewhere (Blank et al. 2012). European guidance for the definition, diagnosis, assessment and intervention of DCD published by the European Academy of Childhood Disability in 2011 was adapted for research and practice in the UK at a series of consensus meetings during 2012 which I attended on behalf of the Dyspraxia Foundation. These meetings culminated in the co-production of a definition of DCD and guidance for teachers, parents, allied health professionals, employers and GPs (<http://www.movementmattersuk.org/dcd-dyspraxia-adhd-spld/uk-dcd-consensus.aspx>). The European guidance and UK definition have been promoted to general practitioners, parents and professionals online (www.movementmattersuk.org; www.dyspraxiafoundation.org.uk), by professional organisations (College of Occupational Therapists 2013a) and in medical literature (Blank et al. 2012). However, while educationalists, including educational psychologists were involved in the consensus meetings there has been less promotion of the UK consensus and guidelines within education, perhaps reflecting the uncertainty and confusion about the diagnosis and terminology which the consensus meetings hoped to address.

DCD/dyspraxia is a relatively 'new' diagnosis compared to other developmental conditions including 'autism' and 'Attention-Deficit Disorder with or without hyperactivity' which were first included as distinct diagnostic categories in the third edition of DSM in 1980. Research relating to DCD/dyspraxia has increased significantly over the last two decades, aided by more consistent use of terminology since the international consensus meeting in 1994 (Magalhães, Missiuna and Wong 2006). A systematic review for development of the European guidelines (Blank et al. 2012) included 372 relevant studies published between 1995 and January 2010. There is a bias in the literature towards school age children (Kirby, Sugden and Purcell 2013) reflecting the emphasis on early identification and intervention, and on impairments at the level of body functions (Blank et al. 2012). Despite the increase in international research there remains a paucity of information regarding the aetiology of DCD; the heterogeneity of the condition has complicated attempts to identify an underlying cause to explain the condition (Kirby, Sugden and Purcell 2013). Furthermore, very few studies address activities and participation (Blank et al. 2012) even though interventions that address the everyday activities and social consequences for children with DCD are more important for many families than those that address underlying motor difficulties (Morgan and Long 2012). Indeed, there are significantly fewer qualitative studies in the field of DCD/dyspraxia than quantitative studies. This imbalance risks prioritizing the views of researchers and academics over the views of those affected by DCD/dyspraxia and could mean that important information about the experience of living with the condition which could have implications for intervention outcomes, might be missed.

Although DCD is a relatively common disorder (the prevalence of DCD of around 5% compares to a prevalence of around 1% for childhood autism in the school-aged population in the UK (Baird et al. 2006)) it receives considerably less funding for research and clinical/educational development than other developmental disorders including autism (Kirby, Sugden and Purcell 2013). The lack of funding and research focus on DCD is frustrating for researchers, clinicians, parents and people living with the condition who recognise the significant impact of motor impairments on daily life (Dunford et al. 2005, Magalhães, Cardoso and Missiuna 2011, Mandich, Polatajko and Rodger 2003, Summers, Larkin and Dewey 2008, Wang et al. 2009). It has been suggested that DCD/dyspraxia represents a significant burden on society because it has long-term implications for health and well-being (Blank et al. 2012). However, evidence of the economic impact of DCD/dyspraxia is limited and cost savings associated with the provision of effective intervention and support may not become apparent for some years (College of Occupational Therapists 2012). Without such information it is difficult to persuade policymakers of the importance of funding services and research into DCD/dyspraxia.

The educational context in which the study is presented is changing. Research suggests that young people with DCD/dyspraxia are usually educated (in the UK) in mainstream schools (Novak et al. 2012). Currently, children with DCD/dyspraxia living in England are covered by the Special Educational Needs (SEN) and Disability Act (Department of Education 2001) if their difficulties affect their ability to make progress and access the curriculum. Some children with DCD/dyspraxia have a Statement of Educational Needs (a 'Statement') which describes the young person's needs and how they will be met. It is not known how many children with DCD/dyspraxia have a Statement as they are included in the categories of children with Specific Learning Difficulties, behaviour, emotional and social difficulties, or speech, language and communication needs depending on their individual profile (<https://www.gov.uk/government/publications/special-educational-needs-in-england-january-2013>). The Department for Education is currently making changes to how young people with special educational needs are supported, including replacing the Statement of Educational Needs with an Education, Health and Care Plan. These changes come into effect in September 2014; their impact on educational provision and support for young people with DCD/dyspraxia will need careful monitoring.

Occupational therapists have an important role with young people with DCD/dyspraxia, including contributing to the diagnosis (Missiuna et al. 2008b); assessing the impact of DCD/dyspraxia on participation in daily life activities (College of Occupational Therapists 2013a); and helping young people to master the tasks and activities that are important to them (Polatajko and Cantin 2006). Occupational therapists also have a role in educating parents and teachers about DCD/dyspraxia

(College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003). Research indicates that occupational therapy is of benefit to children with DCD (Blank et al. 2012, Novak et al. 2012) with task-orientated approaches such as the Cognitive Orientation to Occupational Performance (Mandich and Polatajko 2005, Polatajko, Mandich and Macnab 2001) and other contemporary motor training programmes considered 'best practice' based on current available evidence. A review of occupational therapy services in 2003 (College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003) found the average waiting time for occupational therapy in the UK was 46 weeks. The report concluded that children with DCD/dyspraxia were doubly disadvantaged because children with more severe conditions were often prioritized for assessment and treatment. The situation has changed little in the decade since the report was published. Parents still struggle to gain access to therapy services (Maciver et al. 2011) and feel they have to fight to secure appropriate help and support (Novak et al. 2012). Anecdotal evidence suggests that children with DCD/dyspraxia continue to be a low priority for occupational therapy. The situation is even more acute for teenagers with DCD/dyspraxia who may not be offered a service at all (College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003). The challenge for occupational therapists and other health professionals is to manage increased demand for services as awareness of DCD/dyspraxia rises and more children with increasingly complex conditions are referred, whilst budgets and resources remain static at best or are reduced.

The role of parents/carers in facilitating the motor, social, emotional and cognitive development and performance of children with DCD/dyspraxia has long been recognised (Chesson, McKay and Stephenson 1990, Missiuna et al. 2006b). Parents/carers (as well as the young person and other significant adults) are an important source of information to determine the impact of motor difficulties on everyday activities and whether a child meets criterion B of DSM-V (American Psychiatric Association 2013). Research reinforces the value of working with parents and teachers to maximise therapy resources (Stephenson and Chesson 2008b) while EACD guidance recommends that information and support to parents should be offered before moving to individual or group interventions (Blank et al. 2012). Although parents frequently report having to fight for support for their child (Maciver et al. 2011, Missiuna et al. 2006b, Rodger and Mandich 2005), they now have better access to information via local support groups, the Dyspraxia Foundation (originally the Dyspraxia Trust) and the development of 'virtual' support groups through social media and online discussion forums (Kirby, Edwards and Hughes 2008, Missiuna et al. 2006b, Miyahara et al. 2009). This study is therefore presented in a context where parents/carers are willing to advocate for better

support and resources for their children individually and collectively, and are increasingly empowered through better access to information.

User involvement

As an occupational therapist who believes in client-centred practice (Hammell 2001) and as a Trustee of the Dyspraxia Foundation alongside parents and adults with DCD/dyspraxia, it was important to me that people with DCD/dyspraxia should be involved in this project as co-researchers from the outset. Co-researchers are people who have a personal or professional interest in an area of study and work alongside a researcher, contributing to the investigative process and interpretation of findings. I felt a strong moral obligation to honour the principle of doing “nothing about us without us”, a slogan adopted by UK disability activists in the 1990’s (Charlton 1998). A key and unique part of the research process was therefore to establish a Research Reference Group of older teenagers and young adults with DCD/dyspraxia. Involving young adults as co-researchers in the research design, delivery, analysis and dissemination privileges their experience and knowledge as experts in dyspraxia. There is evidence to suggest that patient and public involvement strengthens the credibility and impact of health and social care research (Staley and Minogue 2006) while the importance and value of public involvement in research is emphasised in the literature (INVOLVE 2012a, Wright et al. 2010) and in UK policy (Department of Health 2006). I was determined that the involvement of a Research Reference Group would be useful and meaningful rather than ‘tokenistic’ (Beresford 2003, McKeivitt, Fudge and Wolfe 2010) and also a respectful and valuable use of members’ time. I hoped that involving the Reference Group would help me to make sense of participants’ experiences by offering an ‘insider perspective’ on the experience of living with DCD/dyspraxia, a crucial element of the IPA approach (Smith 2008). Further background and information about the role of the Reference Group in this study is included in Chapter 3.

Rationale for the use of interpretative phenomenological analysis

The approach chosen for this study, interpretative phenomenological analysis (IPA) (Smith, Flowers and Larkin 2009) was selected as the most appropriate to develop an understanding of the experience of teenagers living with DCD/dyspraxia. It was not the purpose of this study to produce an objective account of DCD/dyspraxia in adolescence; this could be achieved by, for example measuring motor competence, academic achievement or psychological wellbeing. Nor was it intended to identify the causes of the difficulties experienced by adolescents with DCD/dyspraxia. Instead this study sought to offer a detailed view of the meanings teenagers attributed to their individual experience of DCD/dyspraxia. IPA was selected because of its focus on exploring participants’ personal worlds whilst acknowledging the role of the researcher in the process. My knowledge of DCD/dyspraxia developed through my clinical experience as an occupational therapist,

my longstanding association with the Dyspraxia Foundation and my experience as the mother of two teenagers therefore played an essential part in the research process.

Research question and aims

There is a need to understand the lived experience of DCD/dyspraxia and the meanings attached to those experiences from the perspective of people with the condition as this is a neglected area of research. The research question was:

- How is life experienced by adolescents with DCD/dyspraxia from their own contemporaneous perspective?

The study aimed to give voice to teenagers with DCD/dyspraxia whose presence is often missing from the dominant discourse, and to explore how life is experienced by adolescents with DCD/dyspraxia from their own contemporaneous perspective. The study objectives were:

- To identify areas of interest and concern to teenagers with DCD/dyspraxia and to explore teenagers' perspectives on the impact that the condition has on their lives;
- To identify how parents, professionals and organisations such as the Dyspraxia Foundation might provide better support for teenagers with DCD/dyspraxia; and
- To identify directions for future research with teenagers with DCD/dyspraxia.

Summary of the thesis

This chapter introduced the thesis by providing a contextual background to the study, demonstrating that teenagers with DCD/dyspraxia are an important but neglected population in research and occupational therapy practice. Chapter 2 develops this discussion by examining the quantitative and qualitative literature to establish what was already known about how DCD/dyspraxia affects young people during adolescence. The chapter moves on to examine policy and practice to determine how easy it is for teenagers with DCD/dyspraxia to access occupational therapy services. The chapter concludes with a summary of the strengths and weaknesses of the extant literature and identifies the important contribution that this study has to offer.

User involvement is an important aspect of this study. In Chapter 3 I provide the context and a rationale for the involvement of a research Reference Group of older teenagers and young adults in the study, and examine their role in the research design, delivery, analysis and dissemination.

Chapter 4 presents the methodological framework for the study. I justify adopting interpretative phenomenological analysis as the research approach and explore the strengths and limitations of this methodological paradigm with particular reference to its use in occupational therapy research. In the second part of this chapter I set out the research design, including a detailed description of

the process of analysis and the move from the analysis of individual transcripts to a position of analytical interpretation.

Chapter 5 presents the study findings and is divided into five sections, representing the five master themes that emerged and that capture the experience of living with DCD/dyspraxia as a teenager. The findings include quotes as evidence for each theme, rooting analysis firmly in participants' own words (Pringle et al. 2011). In accordance with IPA philosophy, findings are presented in Chapter 5 without reference to the extant literature (Smith, Flowers and Larkin 2009).

In Chapter 6 I review the study findings and consider these in the context of the extant qualitative literature concerning people with DCD/dyspraxia and the wider disability and chronic illness literature focusing on teenagers. This chapter concludes with a review of the extent to which the study findings support or challenge previous research narratives.

Chapter 7 draws the findings together into a conceptual framework that illustrates the lived experience of teenagers with DCD/dyspraxia. The conceptual framework is derived from a review of patterns and connections across the data and is firmly grounded in participants' accounts. Reference is made to the extant literature to contextualize the findings and to demonstrate what the research has added to existing knowledge.

In Chapter 8 I review the methodological process and reflect on my role and influence throughout the research process. Attention is given to involvement of the Reference Group as this is offered as a particular and novel contribution to the practice of IPA.

The thesis concludes in Chapter 9 with a review of the research question and aims. I demonstrate the contribution that this study makes to theory, practice and research, summarising the new understandings about DCD/dyspraxia that the study brought forth and identifying the study's contributions to practice for occupational therapists, teachers and the voluntary agencies that support young people with DCD/dyspraxia. Directions for future research are suggested.

Chapter 2

Literature Review

Chapter 2: Literature Review

The preceding chapter introduced the thesis and its overall structure. It provided a context for the study and illustrated how teenagers with DCD/dyspraxia are an important but neglected population both in research and in occupational therapy practice. The chapter also highlighted that the views and experiences of people affected by DCD/dyspraxia have been largely ignored in the dominant discourse. This chapter develops the discussion by examining available literature about the experience of teenagers living with DCD/dyspraxia.

The process and timing of this literature review was informed by the philosophical beliefs of interpretative phenomenological analysis in which the voice and experience of participants is foregrounded and prioritized (Smith, Flowers and Larkin 2009). Traditionally, researchers undertake a comprehensive and systematic literature review at the start of a research project to determine what is already known, to identify gaps in knowledge and to justify the need for a study (Hart 2001). In IPA however, an open-minded approach to data collection is required to enable participants to raise issues of interest or concern to themselves rather than being driven by the pre-conceptions of the researcher who might make presumptions about possible themes based on previous knowledge (Smith, Flowers and Larkin 2009). The literature review for this study was therefore carried out in two stages: the first during 2009 before data collection commenced, and the second during 2013/14 as part of the interpretative and analytical process.

The purpose of the initial literature review was to take a broad over-view of the research to determine whether my perception that there was a lack of knowledge about DCD/dyspraxia during adolescence was correct. I identified a small number of quantitative studies that followed children with motor coordination difficulties into adolescence and an even smaller number of qualitative studies where parents or adults with coordination difficulties reflected on their teenage years (Cantell and Kooistra 2002; Cantell, Smyth and Ahonen 1994; Cousins and Smyth 2003; Fitzpatrick and Watkinson 2003; Losse et al 1991; Missiuna et al 2007; Rasmussen and Gillberg 2000). I critiqued these papers including the research recommendations, and included this information in my research proposal to support justification for my study.

In qualitative research a literature review is often carried out to inform development of interview questions. In the case of the current study however, interview questions were developed with both reference to the literature and the involvement of a research Reference Group. The role of the Reference Group is discussed in Chapter 3.

A second literature review was carried out using a systematic approach after all interviews and the first stage of group-level analysis was completed. The purpose of this literature review was to develop, contextualize and add depth to my understanding of the themes that had emerged. Delaying carrying out a more comprehensive literature review until this stage of the study enabled me to keep an open mind about possible themes and findings during the initial stages of analysis. This literature review is a synthesis of current knowledge about DCD/dyspraxia in adolescence.

Table 1: Timeline indicating when literature was reviewed as part of the research process.

Timescale	Activity
2009	Broad over-view of literature to provide justification for the study
2010	Data collection: rounds 1,2 and 3
2011	Analysis and development of themes for interview rounds 1,2 and 3
2012	Development of master themes for the whole study
2013	Review of literature to develop understanding of themes and contextualise findings
2014	Synthesis of literature representing knowledge about DCD/dyspraxia in adolescence at the time that the thesis is presented

This literature review is divided into two sections. The first section asks ‘*How does DCD/dyspraxia affect young people during adolescence?*’ while the second asks ‘*How easy is it for teenagers with DCD/dyspraxia to access occupational therapy services?*’ Each section concludes with a summary of the strengths and weaknesses of the current literature. The chapter conclusion provides justification for the study and demonstrates the important contribution that it has to offer.

Whilst considering the aims of this literature review it is important to clarify what this chapter will not cover. Firstly, it is not the aim to provide a historical perspective on the definition and aetiology of DCD/dyspraxia; a discussion about terminology was included in Chapter 1 and co-occurrence of conditions associated with DCD/dyspraxia is examined later in Chapter 4. These issues have also been explored elsewhere (Blank et al. 2012, Polatajko and Cantin 2006, Sugden, Kirby and Dunford 2008, Zwicker et al. 2012). Secondly, this chapter will not offer a critical appraisal of diagnosis and assessment procedures or tools, nor seek to determine the relative effectiveness of different interventions; these areas were the focus of the recent EACD review (Blank et al. 2012). Instead, this chapter will identify what is known about the impact of DCD/dyspraxia on the daily lives of teenagers, and teenagers’ access to health and educational support services. First however, I will describe the process by which relevant studies were identified, critically appraised and synthesised to produce a summary of the best available information about how DCD/dyspraxia affects the lives of teenagers.

Method

The nature and type of literature that would enable me to answer two specific review questions are presented in Table 2.

Table 2: Literature search questions and nature of literature reviewed

Review questions	Nature of literature
1) How does DCD/dyspraxia affect young people during adolescence?	<p><u>Quantitative literature</u></p> <ul style="list-style-type: none"> • Cohort follow-up studies • Cross-sectional evaluations <p>Identifying:</p> <ul style="list-style-type: none"> • Core symptoms: <ul style="list-style-type: none"> ○ Motor skills ○ Academic skills ○ Performance of daily activities/routines • Social, emotional and health consequences • Associated symptoms <p><u>Qualitative literature</u></p> <ul style="list-style-type: none"> • Teenagers' views about the challenges they face • Adults' retrospective views about the challenges they faced during adolescence • Views of parents/carers about the challenges faced by teenagers with DCD/dyspraxia • Professional perspectives on the challenges faced by young people with DCD/dyspraxia during adolescence
2) How easy is it for teenagers with DCD/dyspraxia to access occupational therapy services?	<p>UK policy documents</p> <p>Literature reviewing service provision by allied health professionals</p> <p>Qualitative literature exploring views of parents/carers re accessing services</p>

To answer the first question a search of six relevant databases (Table 3) was carried out to identify professional knowledge about teenagers with DCD/dyspraxia published in peer-reviewed journals. The following search terms were used: developmental coordination disorder*; developmental coordination disorder*; dyspraxi* and clums*. The term 'developmental coordination disorder' was the primary search term, reflecting the decision of the international consensus in 1994 to promote consistency and allow comparison between studies (Polatajko, Fox and Missiuna 1995). The terms 'dyspraxi*' and 'clums*' were also included as these are often used by people living with the

condition to describe themselves (Biggs 2005, Lingam et al. 2014, Miyahara and Register 2000, Novak et al. 2012) and to capture the experience of people with coordination difficulties who did not receive a diagnosis of DCD because the term was not formally recognised until 1987 (American Psychiatric Association 1987). An adolescent age filter was applied to identify studies that included teenagers. The search strategy is included in Appendix A. The last search was run on 31st May 2014.

Table 3: Databases searched

Databases searched
Amed Cinahl Medline PsychINFO Academic Search Complete Eric

Titles of search results were reviewed; if deemed relevant the abstract was retrieved for review. Full-texts of all potentially relevant articles were obtained and examined. Articles that were not peer-reviewed or did not report primary data (e.g. review articles, commentaries) were excluded. Articles in English were selected as resources did not allow for translation.

Database searches were supplemented by following up references in articles and books. This revealed a further 16 studies. Several studies included teenagers with ‘minor neurodevelopmental disorders’ (Gillberg and Gillberg 1989, Gillberg, Gillberg and Groth 1989, Shaffer et al. 1985). These participants met the criteria for ‘probable DCD’ but had not received the diagnosis. Their findings are however relevant to this study and were therefore included in the review.

Table 4: Inclusion/exclusion criteria

Inclusion criteria	Exclusion criteria
Primary research relating to young people aged 13-18 years diagnosed with DCD according to DSM criteria	Primary research relating to young people with acquired dyspraxia
Older research (pre-1994 consensus) relating to teenagers aged 13-18 years for whom DCD /dyspraxia would have been an appropriate diagnosis (probable DCD/dyspraxia)	Primary research relating to children with DCD/dyspraxia with a mean age of 12 years or less, or 19 years and over.
Research relating to teenagers aged 13-18 years with motor coordination difficulties who fit the DSM criteria (probable DCD/dyspraxia)	Research relating to teenagers aged 13-18 years whose motor coordination difficulties could be attributed to other conditions such as cerebral palsy and muscular dystrophy
English language only	Not English language
UK policy documents	Policy documents relating to non-UK countries

The search identified 1364 studies. After duplicates were removed, 1142 study titles were reviewed for relevance. If the title suggested the study might be eligible for inclusion, the abstract was examined (n=378). 261 papers were excluded following abstract screening. Full texts of all potentially relevant papers were obtained and examined (n=117). A list of reviewed but excluded papers (n=79) with reasons for exclusion is provided in Appendix B. A total of 37 relevant papers were identified (Table 5). I carried out a quality assessment of all 37 papers using tools adapted from the Critical Appraisal Skills Programme (CASP) <http://www.casp-uk.net/#>. This tool was chosen as it provides different checklists for evaluating qualitative and quantitative studies and is used internationally to evaluate evidence in health and social care (National Collaborating Centre for Methods and Tools McMaster University, Ontario 16 December 2011). A critical appraisal of included papers is provided in Appendix C.

Figure 3: Flow of information through different phases of the literature review “How does DCD/dyspraxia affect young people during adolescence?”

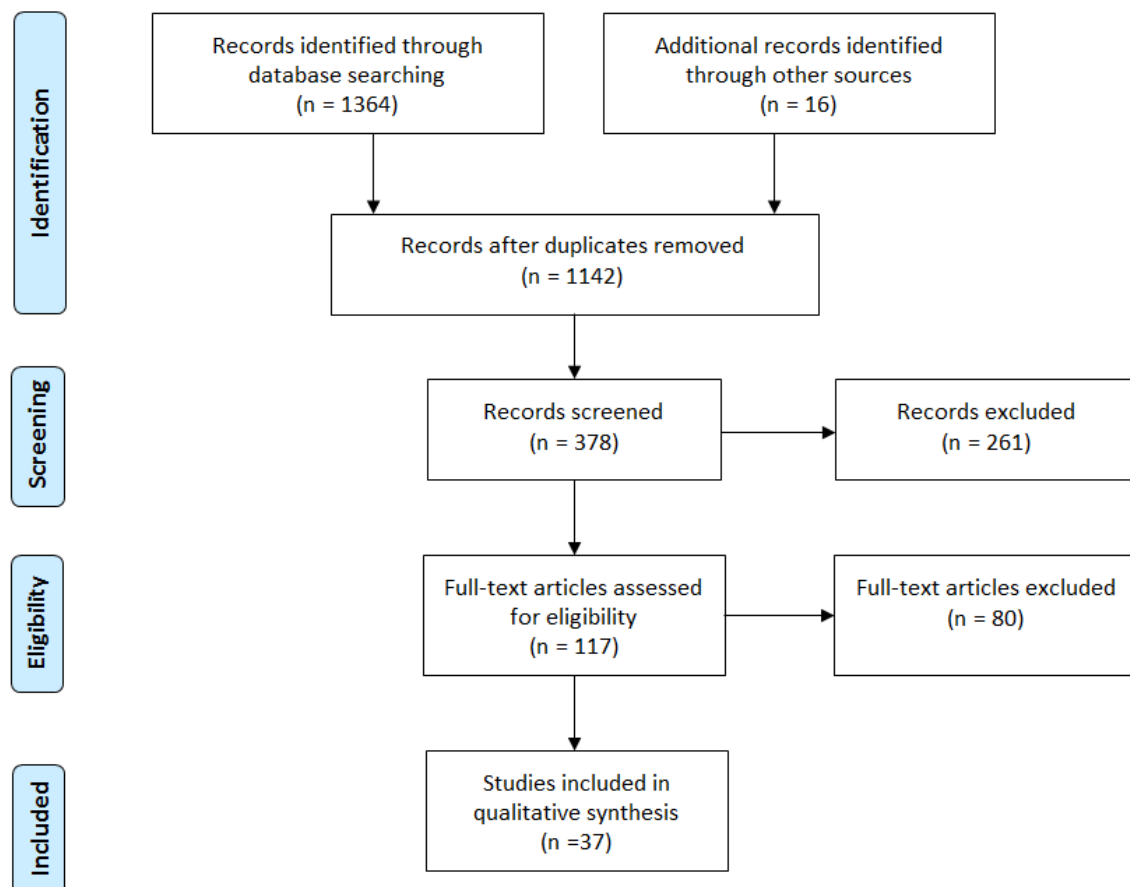


Table 5: Papers included in the literature review

Paper no.	Reference	Study design
1	Barnett, A. L., Dawes, H., and Wilmut, K. (2013) 'Constraints and Facilitators to Participation in Physical Activity in Teenagers with Developmental Co-Ordination Disorder: An Exploratory Interview Study'. <i>Child: Care, Health and Development</i> 39 (3), 393-403	Cross sectional Qualitative
2	Cairney, J., Hay, J., Faught, B. E., Corna, L. M., and Flouris, A. D. (2006) 'Developmental Coordination Disorder, Age, and Play: A Test of the Divergence in Activity-Deficit with Age Hypothesis'. <i>Adapted Physical Activity Quarterly</i> 23 (3) 261-276	Cross sectional Quantitative
3	Cantell, C., Smyth, M., and Ahonen, T. (1994) 'Clumsiness in Adolescence: Educational, Motor and Social Outcomes of Motor Delay Detected at 5 Years'. <i>Adapted Physical Activity Quarterly</i> 11 (2), 115-129	Longitudinal Mixed methods
4	Cantell, M. H., Smyth, M. M., and Ahonen, T. P. (2003) 'Two Distinct Pathways for Developmental Coordination Disorder: Persistence and Resolution'. <i>Human Movement Science</i> 22 (4), 413-431	Longitudinal Mixed methods
5	Cantell, M., Crawford, S. G., and Doyle-Baker, P. (2008) 'Physical Fitness and Health Indices in Children, Adolescents and Adults with High Or Low Motor Competence'. <i>Human Movement Science</i> 27 (2), 344-362	Cross sectional Quantitative
6	Chirico, D., O'Leary, D., Cairney, J., Haluka, K., Coverdale, N. S., Klentrou, P., Hay, J., and Faught, B. E. (2012) 'Longitudinal Assessment of Left Ventricular Structure and Function in Adolescents with Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 33 (2) 717-725	Longitudinal Quantitative
7	Coverdale, N. S., O'Leary, D. D., Faught, B. E., Chirico, D., Hay, J., and Cairney, J. (2012) 'Baroreflex Sensitivity is Reduced in Adolescents with Probable Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 33 (1), 251-257	Cross sectional Quantitative
8	de Oliveira, R. F. and Wann, J. P. (2010) 'Integration of Dynamic Information for Visuomotor Control in Young Adults with Developmental Coordination Disorder'. <i>Experimental Brain Research</i> 205 (3) 387-394	Cross sectional Quantitative
9	de Oliveira, R. F. and Wann, J. P. (2011) 'Driving Skills of Young Adults with Developmental Coordination Disorder: Regulating Speed and Coping with Distraction'. <i>Research in Developmental Disabilities</i> 32 (4) 1301-1308	Cross sectional Quantitative
10	de Oliveira, R. F. and Wann, J. P. (2012) 'Driving Skills of Young Adults with Developmental Coordination Disorder: Maintaining Control and Avoiding Hazards'. <i>Human Movement Science</i> 31 (3) 721-729	Cross sectional Quantitative
11	Eggleston, M., Hanger, N., Frampton, C., and Watkins, W. (2012) 'Coordination Difficulties and Self-Esteem: A Review and Findings from a New Zealand Survey'. <i>Australian Occupational Therapy Journal</i> 59 (6), 456-462	Cross sectional Postal survey
12	Fitzpatrick, D. and Watkinson, E. J. (2003) 'The Lived Experience of Physical Awkwardness: Adults' Retrospective Views'. <i>Adapted Physical Activity Quarterly</i> 20, 279-297	Cross sectional Qualitative
13	Geuze, R. and Borger, H. (1993) 'Children Who are Clumsy: Five Years Later on'. <i>Adapted Physical Activity Quarterly</i> 10, 10-21	Longitudinal Mixed methods

14	Gillberg, I. C. and Gillberg, C. (1989) 'Children with Preschool Minor Neurodevelopmental Disorders IV: Behaviour and School Achievement at Age 13'. <i>Developmental Medicine & Child Neurology</i> 31, 3-13	Longitudinal Quantitative
15	Gillberg, I. C., Gillberg, C., and Groth, J. (1989) 'Children with Preschool Minor Neurodevelopmental Disorders V: Neurodevelopmental Profiles at Age 13'. <i>Developmental Medicine & Child Neurology</i> 31, 14-24	Longitudinal Quantitative
16	Hellgren, L., Gillberg, C., Gillberg, I. C., and Enerskog, I. (1993) 'Children with Deficits in Attention, Motor Control and Perception (DAMP) almost Grown Up: General Health at 16 Years'. <i>Developmental Medicine & Child Neurology</i> 35, 881-892	Longitudinal Quantitative
17	Hellgren L, Gillberg C, Gillberg IC (1994) 'Children with deficits in attention, motor control & perception (DAMP) almost grown up: the contribution of various background factors to outcome at age 16 years' <i>European Child and Adolescent Psychiatry</i> 3 (1) 1-15	Longitudinal Mixed methods
18	Knight, E., Henderson, S., Losse, A., and Jongmans, M. (1992) 'Clumsy at Six - Still Clumsy at Sixteen: The Educational and Social Consequences of having Motor Difficulties in School' in <i>Sport and Physical Activity - Moving Towards Excellence</i> . ed. by Williams, T., Almond, L., and Sparkes, A. London: E & FN Spon, 249-259	Longitudinal Mixed methods
19	Kwan, M. Y. W., Cairney, J., Hay, J. A., and Faught, B. E. (2013) 'Understanding Physical Activity and Motivations for Children with Developmental Coordination Disorder: An Investigation using the Theory of Planned Behavior'. <i>Research in Developmental Disabilities</i> 34 (11) 3691-3698	Cross sectional Mixed methods
20	Lingam, R. P., Novak, C., Emond, A., and Coad, J. E. (2014) 'The Importance of Identity and Empowerment to Teenagers with Developmental Co-Ordination Disorder'. <i>Child: Care, Health and Development</i> 40 (3), 309-318	Cross sectional Qualitative
21	Losse, A., Henderson, S., Elliman, S., Hall, D., Knight, E., and Jongmans, M. (1991) 'Clumsiness in Children - do they Grow Out of it? A 10 Year Follow-Up Study'. <i>Developmental Medicine & Child Neurology</i> 33, 55-68	Longitudinal Mixed methods
22	Missiuna, C., Moll, S., King, S., Law, M., and King, G. (2006) "'Missed and Misunderstood": Children with Coordination Difficulties in the School System'. <i>International Journal of Special Education</i> 21 (1), 53-67	Cross sectional Qualitative
23	Missiuna, C., Moll, S., King, G., and Law, M. (2007) 'A Trajectory of Troubles: Parents' Impressions of the Impact of Developmental Coordination Disorder'. <i>Physical and Occupational Therapy in Pediatrics</i> 27 (1), 81-101	Cross sectional Qualitative
24	Missiuna, C., Moll, S., King, G., Stewart, D., and Macdonald, K. (2008) 'Life Experiences of Young Adults Who have Coordination Difficulties'. <i>Canadian Journal of Occupational Therapy</i> 75 (3), 157-166	Cross sectional Qualitative
25	Payne, S., Ward, G., Turner, A., Taylor, M. C., and Bark, C. (2013) 'The Social Impact of Living with Developmental Coordination Disorder as a 13-Year-Old'. <i>The British Journal of Occupational Therapy</i> 76 (8), 362-369	Cross sectional Qualitative

26	Piek, J. P., Baynam, G. B., and Barrett, N. C. (2006) 'The Relationship between Fine and Gross Motor Ability, Self-Perceptions and Self-Worth in Children and Adolescents'. <i>Human Movement Science</i> 25 (1), 65-75	Cross sectional Quantitative
27	Piek, J. P., Rigoli, D., Pearsall-Jones, J. G., Martin, N. C., Hay, D. A., Bennett, K. S., and Levy, F. (2007) 'Depressive Symptomatology in Child and Adolescent Twins with Attention-Deficit Hyperactivity Disorder and/or Developmental Coordination Disorder'. <i>Twin Research and Human Genetics</i> 10 (04), 587-596	Cross sectional Quantitative
28	Rigoli, D., Piek, J. P., and Ooserlann, J. (2012) 'An Examination of the Relationship between Motor Coordination and Executive Functions in Adolescents'. <i>Developmental Medicine & Child Neurology</i> 54, 1025-1031	Cross sectional Quantitative
29	Rigoli, D., Piek, J. P., and Kane, R. (2012) 'Motor Coordination and Psychosocial Correlates in a Normative Adolescent Sample'. <i>Pediatrics</i> 129 (4), e892-e900	Cross sectional Quantitative
30	Shaffer, D., Schonfeld, I., O'Connor, P., Stokman, C., Trautman, P., Shafer, S., and Ng, S. (1985) 'Neurological Soft Signs: Their Relationship to Psychiatric Disorder and Intelligence in Childhood and Adolescence'. <i>Archives of General Psychiatry</i> 42 (4), 342-351	Longitudinal Mixed methods
31	Sigurdsson, E., van Os, J., and Fombonne, E. (2002) 'Are Impaired Childhood Motor Skills a Risk Factor for Adolescent Anxiety? Results from the 1958 U.K. Birth Cohort and the National Child Development Study'. <i>American Journal of Psychiatry</i> 159, 1044-1046	Historic cohort Quantitative
32	Skinner, R. A. and Piek, J. P. (2001) 'Psychosocial Implications of Poor Motor Coordination in Children and Adolescents'. <i>Human Movement Science</i> 20 (1-2), 73-94	Cross sectional Quantitative
33	Soorani-Lunsing, R. J., Hadders-Algra, M., Huisjes, H. J., and Touwen, B. C. L. (1994) 'Neurobehavioural Relationships After the Onset of Puberty'. <i>Developmental Medicine & Child Neurology</i> 36 (4), 334-343	Longitudinal Quantitative
34	Stephenson, E. A. and Chesson, R. A. (2008) 'Always the Guiding Hand': Parents' Accounts of the Long-Term Implications of Developmental Coordination Disorder for their Children and Families'. <i>Child: Care, Health and Development</i> 34 (3), 335-343	Cross sectional Qualitative
35	Visser, J., Geuze, R., and Kalverboer, A. (1998) 'The Relationship between Physical Growth, the Level of Activity and the Development of Motor Skills in Adolescence: Differences between Children with DCD and Controls'. <i>Human Movement Science</i> 17, 573-608	Longitudinal Quantitative
36	Wagner, M. O., Kastner, J., Petermann, F., Jekauc, D., Worth, A., and Bös, K. (2011) 'The Impact of Obesity on Developmental Coordination Disorder in Adolescence'. <i>Research in Developmental Disabilities</i> 32 (5), 1970-1976	Cross sectional Quantitative
37	Wilmot, K. and Wann, J. (2008) 'The use of Predictive Information is Impaired in the Actions of Children and Young Adults with Developmental Coordination Disorder'. <i>Experimental Brain Research</i> 191 (4) 403-418	Cross sectional Quantitative

The following section synthesises and critically reviews the literature regarding the experience of teenagers with DCD/dyspraxia.

How does DCD/dyspraxia affect young people during adolescence?

Despite a previously-held common belief that children would grow out of their motor difficulties (Hall 1988), a small but significant number of longitudinal studies suggest that for many young people difficulties associated with the condition persist into adolescence; moreover, there is growing evidence of the continuing impact of poor motor coordination into adulthood (Cousins and Smyth 2003, Fitzpatrick and Watkinson 2003, Kirby, Edwards and Sugden 2011). Research also indicates that DCD/dyspraxia extends beyond the motor domain, impacting on social, emotional and behavioural outcomes in adolescence. This section explores what is known about motor skills associated with DCD/dyspraxia during adolescence and their impact on activities of daily living and academic performance. These are the core symptoms of DCD as defined in DSM-V. This section then moves on to examine the social and emotional outcomes and symptoms associated with DCD/dyspraxia during adolescence. This knowledge is mainly derived from the quantitative literature. This section is followed by a review of the qualitative data exploring the lived experience of DCD/dyspraxia during adolescence. Many of the studies cited in this review commenced before the inclusion of DCD in DSM-III and the international consensus agreement in 1994. For the purposes of this review therefore, the term 'probable DCD/dyspraxia' is used to refer to participants for whom DCD would have been an appropriate diagnosis.

Motor problems in adolescence

A small number of longitudinal studies examined the long-term motor consequences of DCD/dyspraxia identified in childhood. The findings of three cohort studies indicate that around half of young people identified with probable-DCD/dyspraxia between 5-7 years had significantly poorer motor coordination than their peers when re-tested during adolescence (Cantell, Smyth and Ahonen 1994, Geuze and Borger 1993, Losse et al. 1991). Authors such as Cantell, Smyth and Ahonen (2003) and Geuze and Borger (1993) argue that the persistence of motor difficulties is linked to their severity in childhood as children with the poorest scores for motor coordination continued to perform poorly in adolescence, while those with milder difficulties differed less from controls as they grew older. Furthermore, those with severe and persistent motor difficulties were more likely to experience adverse social, emotional and academic outcomes than their peers, an association explored later in this section.

While evidence indicates that childhood motor difficulties persist into adolescence for some young people (e.g. Geuze and Borger 1993, Gillberg, Gillberg and Groth 1989, Losse et al. 1991) other

studies identify a group whose motor coordination improves over time, providing some support for Hall's argument that (some) children grow out of DCD/dyspraxia (Hall 1988). Soorani-Lunsing et al (1994) followed-up a group of children with minor neurological dysfunction (MND) at ages 9 and 13 finding that MND had resolved in some cases, but persisted in others. The researchers hypothesized that transient MND was caused by immaturities in the development of the nervous system which continued to develop and improve over time. Likewise Visser et al (1998) carried out a comparative study of boys aged 11-14 years with and without DCD, finding that the difference in motor skills between boys with DCD and those without decreased with age; furthermore, adolescents with DCD were less affected by the adolescent growth spurt than the control group. The authors suggest neurological immaturity as an explanation for the coordination difficulties of those young people with DCD who appeared to 'catch up' with their peers and who benefitted from effects co-occurring with the adolescent growth spurt. Caution should be taken when interpreting Visser's findings however, as the 'catching up' phenomenon might be explained by a ceiling effect of the tests used rather than neurological maturity. Norms for young people aged 11-12 years were applied throughout the study even though participants were 14 when it concluded; therefore boys with DCD who had lower scores when first tested had more opportunity to improve their scores, whereas the control group had less room for improvement so the gap in performance narrowed over time.

There are several factors making it difficult to interpret the findings of studies examining the motor outcome of DCD/dyspraxia in adolescence. The first relates to the motor assessments used as it is only recently that standardised motor assessments have become available for young people aged 12+ (Bruininks and Bruininks 2005, Henderson and Sugden 2007). Early studies by Shaffer (1985) and Gillberg and colleagues (1989) relied on clinical observations of neurological soft signs. Whilst the authors took measures to enhance reliability (such as checking inter-rater reliability and using assessors who were blind to the study groups) the findings could be criticised for their subjectivity. Other researchers adopted tools that were developed for a younger population (Geuze and Borger 1993, Losse et al. 1991). As with Visser's study however, the ceiling effect associated with using younger age norms make the findings unreliable. Other researchers adapted adult assessments (Cantell, Smyth and Ahonen 1994), but using adult norms may result in an under-estimation of motor difficulties, limiting the significance of study findings.

Secondly, variations in the methods used to determine outcomes make it difficult to compare studies. Some studies compare young people with DCD to a control group (Cantell, Smyth and Ahonen 1994, Geuze and Borger 1993, Losse et al. 1991) while others compare the sample's

progress to their original assessment findings (Gillberg, Gillberg and Groth 1989, Soorani-Lunsing et al. 1994).

Despite these limitations, all studies provide evidence of the heterogeneity of motor skills among teenagers with DCD/dyspraxia. Individuals studied by Visser et al (1998) differed significantly in their rate of improvement over time, while Geuze and Borger (1993) demonstrated that persistent motor difficulties were not consistently related to the particular skills that were tested. The findings therefore suggest that improvements in motor skills that may occur over time do not occur in a homogenous pattern (Cantell, Smyth and Ahonen 2003). Furthermore, differences in outcome may be affected by other factors including IQ, co-occurrence of associated conditions and environmental factors: these factors are considered later in this chapter.

Impact of DCD/dyspraxia on activities of daily living

As indicated in DSM-V for a diagnosis of DCD to be made there should be evidence that motor difficulties significantly interfere with activities of daily living and/or academic performance (American Psychiatric Association 2013). Clinicians and researchers have however found it difficult to implement this criterion because of a lack of objective and standardised tools. Assessment of performance of activities of daily living is also complicated by contextual differences affecting the acquisition and importance of these activities across cultures (Blank et al. 2012). No quantitative studies examining the self-care performance of adolescents with DCD/dyspraxia were found. While the recently updated DCDQ offers the promise of a standardised tool for measuring the performance of everyday activities of children with DCD up to the age of 15 (Wilson et al. 2009), its psychometric properties remain the subject of debate (Pannekoek et al. 2012, Rivard et al. 2014, Wilson et al. 2009) and its use with adolescents has not yet been reported.

Academic performance

Evidence that motor difficulties impact on academic performance is included in criterion B of the DSM-V diagnostic criteria for DCD (American Psychiatric Association 2013). Several studies examine the academic performance of adolescents with DCD/dyspraxia, either as the primary or a secondary aim. Most report that many but not all young people with poor motor coordination do less well academically than their peers, identifying school subjects with a practical component such as drawing, music and PE as a particular challenge (Losse et al. 1991). Piek et al (2006) report a strong association between poor fine motor skills and poor academic performance among teenagers with probable-DCD/dyspraxia although no such relationship was found in relation to poor gross motor skills. This finding seems reasonable as handwriting is the primary means by which learning is demonstrated. Moreover, research demonstrates that lower grades are often given to poorly presented work compared to work that is well presented, even when the content of the work is

equivalent (Feder and Majnemer 2007). Teenagers with fine motor and handwriting difficulties are therefore at greater risk of academic underachievement than their well-coordinated peers. While Piek et al's (2006) findings seem valid, it should be noted that participants were categorised as with or without DCD by their performance on a standardised motor assessment but the impact of poor motor ability on activities of daily living was not examined; furthermore, the absence of a neurological or intellectual disability was established by reports rather than formal assessment. The findings of this study should therefore, be interpreted with caution.

Some studies report an association between poor academic outcomes and lower IQ among teenagers with probable-DCD/dyspraxia (Cantell, Smyth and Ahonen 1994, Cantell, Smyth and Ahonen 2003, Shaffer et al. 1985). Worryingly, Losse et al (1991) reported that a group of children identified with poor coordination at age 6 were doing less well academically than their peers at age 16, even though their measured intelligence was comparable to the control group 10 years previously. This was despite teachers reporting that the 'clumsy' group applied a similar amount of effort to their peers at school. Cantell et al (1994) found that young people with persistent motor difficulties at age 15 had lower educational aspirations than their peers; furthermore, by age 17 several were unemployed unlike their well-coordinated peers (Cantell, Smyth and Ahonen 2003). These findings suggest a concerning pattern of under-achievement in teenagers with probable-DCD/dyspraxia.

A range of additional factors affecting the learning and academic performance of adolescents with probable-DCD/dyspraxia have been identified. In a study by Gillberg and Gillberg (1989) 40% of teenagers with motor problems alone had poor academic achievement, yet when severe motor problems were combined with attention problems 85% had poor school achievement (compared to 30% of the comparison group). The number of participants in each group was small however, making it difficult to generalise the findings. Teachers in the study by Knight et al (1992) described similar adverse effects of poor attention and concentration on the academic performance of teenagers with probable-DCD/dyspraxia. Their findings suggest that the combination of personal factors (including poor motor skills and attention) and their interaction with the environment has a negative impact on the academic achievement of teenagers with DCD/dyspraxia. The academic outlook is not however poor for all teenagers with previously-identified coordination difficulties. In the study by Losse and colleagues for example (1991), two out of 15 participants who had scored poorly on motor tests at age 6 were performing well academically at age 16.

Studies suggest that teenagers' self-perceptions of scholastic competence, as opposed to their academic achievement are inconsistent. Teenagers with probable-DCD/dyspraxia in studies by Losse

et al (1991), Piek et al (2006) and Cantell et al (2003) reported lower perceptions of academic competence than the comparison groups, but this was not the case for participants in the study by Piek and Skinner (2001). However, the study by Piek and Skinner (2001) included more girls than boys which might account for the different findings. Studies suggest that perceptions of scholastic competence are influenced by a variety of environmental and social factors, including the value that an individual places on learning; thus perceptions of scholastic ability do not necessarily reflect actual academic performance.

Social and behavioural outcomes

Social and behavioural outcomes for teenagers with childhood motor difficulties have been reported by several researchers, often as the secondary focus of a study. Losse et al (1991) reported that young people with probable-DCD/dyspraxia were more likely to be bullied and socially isolated than their better coordinated peers at age 16. Likewise, parents in the study by Geuze and Borger (1993) felt that their children were socially vulnerable, had less developed social contacts and fewer friends than the comparison group. Cantell et al (2003) suggested that teenagers with DCD were at a younger stage of identity development than their age peers and those with less severe motor impairment which might account in part for their social difficulties. Immaturity in identity development might also contribute to the variation in perceived social competence and acceptance reported in different studies. Teenagers with probable-DCD/dyspraxia in a study by Knight et al (1992) for example, reported lower perceived social competence than comparison groups while those in the study by Skinner and Piek (2001) reported poorer social support. However no such differences were reported by Cantell et al (1994). Perceptions of social competence and acceptance may be affected by gender: boys with DCD in the study by Cantell et al (2003) reported fewer close friends than girls, while girls in the study by Piek et al (2005) did not report poor social competence, although boys did. Social competence is a complex construct involving a combination of social, emotional, cognitive and behavioural skills. As demonstrated previously, cognitive development may be impaired in some teenagers with DCD/dyspraxia whilst research also suggests an association between DCD/dyspraxia and anxiety and depression which may affect motivation to engage in social situations (emotional outcomes are discussed in more detail later in this section). Research suggests therefore that the relationship between DCD/dyspraxia and social behaviour is complex and influenced by a variety of individual and contextual factors.

Few studies have explored the spare time activities of teenagers with DCD/dyspraxia. Participants with probable DCD/dyspraxia in the study by Cantell et al (1994) reported fewer spare time activities than the comparison group, while those in the study reported by Knight et al (1992) participated in fewer sports than well- coordinated peers. Teenagers with DCD in a study by Cairney et al (2006)

also participated in fewer organised and free play activities than their peers. While the study did not find that teenagers became more inactive with age compared to their peers, the authors concede that their sample may have been too small and their data gathering tool too insensitive to demonstrate a significant difference. Kwan et al (2013) suggest however, that teenagers with DCD/dyspraxia are less motivated to participate in activities where poor motor skills might affect their success; reduced participation may therefore limit opportunities to develop and rehearse social skills which will have a further negative impact on social confidence.

Antisocial behaviours, including getting into trouble with the police were reported in young people with poor motor coordination in studies by Losse et al (1991) and by Gillberg and colleagues (Gillberg and Gillberg 1989, Gillberg, Gillberg and Groth 1989, Hellgren et al. 1993, Rasmussen and Gillberg 2000). The risk of negative social and behavioural outcomes was associated with the severity of coordination difficulties and the co-occurrence of probable-DCD and poor attention (Gillberg and Gillberg 1989, Hellgren, Gillberg and Gillberg 1994). Other factors that predicted poor behavioural outcomes for young people with motor and attention difficulties included poor reading skills at age 10; low performance IQ at age 7; the presence of autistic traits at age 7; and high antisocial and depression scores at age 10 (Hellgren, Gillberg and Gillberg 1994). Gillberg et al (1989) noted however, that clinically-significant behavioural difficulties were seen in young people previously identified with mild motor and attention impairment even when neurological signs of their dysfunction had lessened, suggesting that secondary social and behavioural consequences of childhood motor impairment may persist into adolescence, even when motor coordination has improved.

Emotional outcomes

Studies identify a relationship between DCD/dyspraxia and an increased risk of poor emotional outcomes in adolescents. An early study by Shaffer et al (1985) reported that the presence of neurological soft signs (such as mirror movements, dysdiadochokinesis and astereognosis) at age 7 increased the likelihood of a psychiatric disorder in adolescence, in particular anxiety and social withdrawal. The relationship between neurological soft signs and anxiety/social withdrawal was present even when anxiety was not apparent at age 7. These findings are consistent with those of Gillberg and Gillberg (1989) who showed that depression was more common in young people with perceptual motor impairments as they grew older. A large scale prospective cohort study reported by Sigurdsson et al (2002) found that boys with motor impairment were three times more likely than the comparison group to experience persistent anxiety at ages 11 and 16; the same effect was not however observed in girls. High levels of adolescent anxiety in young people with DCD were also reported by Skinner and Piek (2001). By contrast, higher levels of anxiety were not reported by

young people with dyspraxia who participated in a survey by Eggleston et al (2012), even though 15% of the sample were described by parents as having an anxiety disorder: the researchers suggest that poor test sensitivity could account for this unexpected finding.

DCD/dyspraxia has been associated with a high risk for depressive symptoms in adolescence. Piek et al (2007) identified higher levels of depressive symptomatology in twins with DCD and DCD/ADHD combined compared to their non-affected siblings. Findings from this study suggest that the increase in depressive symptoms is due to unique environmental factors such as academic, behavioural and social difficulties, rather than genetic factors. The authors suggest that negative social feedback, negative self-perceptions and academic under-achievement might predispose adolescents with DCD (with or without ADHD) to increased levels of depressive symptoms. Rigoli et al (2012) concur, further arguing that the association between motor coordination and emotional outcomes is mediated by an individual's perceptions of competence.

Studies of self-perception in teenagers with DCD/dyspraxia suggest a heterogeneous profile of self-perceived competence. Most found that teenagers with probable DCD/dyspraxia had lower perceptions of their physical competence than comparison groups, perhaps reflecting a more realistic evaluation of their motor ability as they aged. Skinner and Piek (2001) identified an association between lower self-worth and lower self-perceived social acceptance, athletic competence and physical appearance in adolescents with probable DCD/dyspraxia. A later study by Piek et al (2006) reported that the risk of lower self-worth was greatest in boys with poor gross motor skills whereas the self-worth of girls with DCD was lower than that of their peers, regardless of whether fine or gross motor skills were more affected. The findings of these studies suggest that perceptions of athletic competence have a particular influence on global self-worth and the emotional well-being of adolescent boys. However, other personal (including gender) and environmental factors also contribute to teenagers' global self-esteem and self-worth.

Associated symptoms

There is growing evidence of an association between DCD/dyspraxia and conditions including ADHD, overweight/obesity and poor executive functioning. Early studies reported the overlap between probable DCD/dyspraxia and ADHD at around 50% (Gillberg, Gillberg and Groth 1989) although more recently a lower percentage of 10% has been reported (Eggleston et al. 2012). 10% of respondents in Eggleston's survey of parents/carers of young people with DCD/dyspraxia (mean age 13 years) who were members of the New Zealand Dyspraxia Support group described their children as having a coexisting diagnosis of ADHD. The authors explain the lower reported prevalence of ADHD compared to other studies by suggesting that parents are most likely to become members of a

support group for the condition that causes them the most challenge in their daily lives; ADHD was therefore likely to be under-represented in the Dyspraxia Support Group sample. The response rate for Eggleston's postal survey was also poor (20%) and diagnosis was based on parental report and not confirmed by formal testing. The combination of ADHD and poor motor coordination has however been identified as a particular risk factor for a range of negative outcomes including poor academic achievement, psychiatric disorder and depression/anxiety. Piek et al (2007) found that twins with ADHD and DCD combined had higher levels of depressive symptoms than adolescents with DCD or ADHD only; similar findings were reported by Hellgren et al (1994) who also identified a higher risk of accidents requiring hospital treatment, speech and language disorder and substance abuse in boys with combined ADHD/probable-DCD than the comparison group (there were too few girls in the study to make appropriate comparisons). However, as has been described elsewhere in this section, the outlook for some participants with combined ADHD/probable-DCD was more positive, suggesting that negative outcomes could not necessarily be predicted.

There is emerging evidence of an association between DCD/dyspraxia and overweight/obesity in young people (Wagner et al. 2011) which has a negative impact on cardiovascular (Coverdale et al. 2012) and physical fitness (Cantell, Crawford and Doyle-Baker 2008) in adolescence. Cantell et al (2008) found that poor motor skills and static balance were significant predictors of high body mass index; furthermore, a comparison of results for children (aged 8-9 years), adolescents (aged 17-18 years) and adults (aged 20-60) suggest a potential risk of back problems, low bone mineral density, obesity and cardiovascular disease as a function of age in people with poor motor competence. Wagner et al (2011) suggest that obese children may be more at risk of poor motor coordination in adolescence because they have a unique set of physiological, biomechanical and neuromuscular symptoms making them more susceptible to consolidating a pre-existing coordination difficulty. It could be suggested however, that a less active lifestyle limits opportunities for obese adolescents to train and challenge their postural control and other motor skills. Gender may also be a factor influencing the presence of coordination difficulties in overweight adolescents, as girls are generally more skilled at balance and postural control than boys, and DCD is more prevalent in boys than girls (Lingam et al. 2009).

There is emerging research exploring the relationship between motor coordination, executive functions and motor response times in adolescents. Research by de Oliveira et al (2010; 2011; 2012), Rigoli et al (2012) and Wilmut and Wann (2008) indicate that teenagers with DCD have a slower performance speed on visuo-motor and inhibition tasks compared to typically developing peers. Young people with DCD take longer to process visual information and to adjust their movements

accordingly, which has implications for their safety and control when steering. Rigoli et al (2012) revealed an unexpected relationship between balance and total errors for inhibition and attention shifting tasks which suggests that adolescents with DCD have to pay additional attention to maintaining their posture which affects the speed and accuracy of task performance. This interesting finding which supports the need for early intervention to develop balance and postural stability to minimise the additional attentional resources required as task demands and environmental challenges increase during adolescence, requires further investigation.

Review of the qualitative literature

A review of the qualitative literature identified only eight studies exploring the experience of teenagers with DCD/dyspraxia although some of the quantitative studies cited earlier in this chapter included a qualitative element. Respondents included parents, adults with probable DCD/dyspraxia reflecting on their teenage years, and teenagers themselves.

Unsurprisingly, given that DCD/dyspraxia is defined as a disorder of motor coordination the experience of participation in sports and physical activity emerged as a common theme. Parents (Barnett, Dawes and Wilmot 2013, Stephenson and Chesson 2008) and people living with DCD/dyspraxia (Barnett, Dawes and Wilmot 2013, Fitzpatrick and Watkinson 2003, Knight et al. 1992, Missiuna et al. 2008a, Payne et al. 2013) expressed that persistent motor difficulties affected teenagers' participation in and enjoyment of sport and physical activities. Perceived internal constraints to participation were poor motor skills, lack of motivation and fatigue, while external (or indirect) constraints included difficulty travelling to activities, negative comments from peers, and a lack of understanding of DCD/dyspraxia by instructors (Barnett, Dawes and Wilmot 2013, Payne et al. 2013). Even when motor coordination had improved by adolescence, research findings suggest that teenagers' confidence and motivation to engage in physical activities was affected by previous failures and negative experiences (Stephenson and Chesson 2008). Adults with coordination difficulties recalled frequent, pervasive and enduring humiliation and embarrassment because of their failure to adequately perform physical tasks in front of others as teenagers. These feelings and experiences made them anxious that poor coordination would cause them further embarrassment (Fitzpatrick and Watkinson 2003). Teenagers adopted a variety of strategies to avoid situations that might expose their difficulties, for example, by feigning illness or playing truant, or by taking on alternative roles such as keeping score or coaching to avoid drawing attention to their inabilities (Fitzpatrick and Watkinson 2003, Missiuna et al. 2008a).

Yet despite coordination difficulties, research findings have suggested some teenagers with DCD/dyspraxia enjoy sports and were motivated to participate in physical activities to keep fit and

healthy (Barnett, Dawes and Wilmot 2013, Lingam et al. 2014). Furthermore, young people with milder motor difficulties in the study by Cantell et al (1994) were very determined and invested a lot of time and effort into their physical activities even though this did not lead to any great success. While some teenagers expressed a dislike of formal or competitive team games, others wanted to be more physically active and were motivated when they found an activity that they enjoyed (Barnett, Dawes and Wilmot 2013, Lingam et al. 2014) and which matched their physical ability (Missiuna et al. 2008a).

Relationships with peers emerged as a common theme across studies, reflecting adolescence as a time when peer influences play an increasingly important role in the development of teenagers' social confidence and identity. Participants in the studies by Cantell et al (1994) and Payne et al (2013) felt a sense of belonging with peers who shared similar interests. Friends who shared their interests and values were also a source of emotional and practical support at school (Lingam et al. 2014, Payne et al. 2013) although friendships with peers who had their own additional needs sometimes created tensions and conflicts in their relationship (Payne et al. 2013). Bullying was highlighted as a concern in several studies (Lingam et al. 2014, Payne et al. 2013, Stephenson and Chesson 2008) and for some participants had serious negative consequences for their self-esteem and emotional well-being. There was a sense however, that for many, social pressures became less of a concern as teenagers grew older; young adults in the study by Missiuna et al (2008a) for example, felt increasingly accepted by peers who placed a higher value on personality over performance as they matured.

The qualitative literature suggests two developmental trajectories for young people with DCD/dyspraxia during adolescence. Parents in a study by Missiuna et al (2007) became less concerned about their children's motor difficulties but more concerned about their social and emotional well-being as a consequence of changing environmental contexts and increased social and academic expectations during adolescence. Parents of four of the six older children in this study had sought specialist help for their child's emotional well-being while the two oldest had been diagnosed with a major mental illness that included features of anxiety and depression. Similar findings were reported by Stephenson and Chesson (2008); four of the 12 parents interviewed had sought help from child and adolescent mental health services for their children. In another study by Missiuna et al (2007) parents reported that feelings of failure and low self-esteem increased as their children became more aware of their limitations over time; their limitations were also obvious to their peers leading to social problems inside and outside school. By contrast, studies in which young people with DCD/dyspraxia describe their own experiences were more positive. Whilst participants in the study

by Lingam et al (2014) reported continued difficulties with school activities, sports and other day to day tasks, many considered that their difficulties were challenges to be overcome and were optimistic for the future. While some were less confident in their abilities, many had developed strategies or worked hard to acquire everyday life skills. Their optimism reflects that of young adults in the study by Missiuna et al (2008a) who reported improved coping skills during adolescence and early adulthood. They benefitted from decreased demands for physical performance (for example they could type, rather than write) and the opportunity to select school subjects and extra-curricular activities that better matched their strengths. These studies suggest that teenagers adapted to their coordination difficulties over time and perceived a greater ability to create more positive situations for themselves as they grew older.

Strengths and limitations of the extant research literature

Although research involving teenagers with DCD/dyspraxia is limited, what exists has been carried out internationally. There remains a bias towards quantitative research but, in contrast to research involving younger children studies involving teenagers with DCD/dyspraxia have examined the impact of motor difficulties on activities and participation as well as body functions. There is also some evidence of the impact of DCD/dyspraxia on academic performance and leisure activities. The review indicates however, that there remains a paucity of evidence regarding the impact of DCD/dyspraxia on functional daily living skills of importance to teenagers (DSM-V criterion B) (American Psychiatric Association 2013).

By their very nature, longitudinal cohort studies take a long time to carry out, but their findings offer valuable information about the long term outlook for young people with DCD/dyspraxia. All follow-up studies cited in this review commenced before there was international agreement regarding terminology and criteria for diagnosing DCD, making it difficult to be certain that they describe similar populations. Furthermore, with the exception of the study reported by Losse et al (1991) and Knight et al (1992) all other longitudinal studies took place outside the UK. Different cultures, school systems and health care provision will affect developmental outcomes and therefore the transferability of findings to a UK population. The Avon Longitudinal Study of Parents and Children (ALSPAC), a birth cohort study following mothers and their children who were born in a particular area of the UK between 1991 and 1992, includes 346 children who met criteria for probable-DCD at age 7 years (Lingam et al. 2010), offering the promise of further insights into the long-term outlook for children with DCD in the UK in the future.

Different methods for recruiting participants should be considered when interpreting findings and determining a study's impact. Some participants were selected by teachers who identified them as

having motor difficulties (Geuze and Borger 1993, Losse et al. 1991, Visser, Geuze and Kalverboer 1998) while others were identified through population screening (Cantell, Smyth and Ahonen 1994, Hellgren, Gillberg and Gillberg 1994). The ability of teachers to correctly identify children with motor difficulties has been challenged (Junaid et al. 2000, Rivard et al. 2007). There is the risk that only those with more severe coordination problems are identified by teachers so that the challenges faced by young people with milder motor difficulties may be under-represented. This may also be the case for studies where participants were drawn from a clinical population: young people must meet a particular threshold to justify referral to a health professional which could lead to an overestimate of associations between factors and an under-representation of young people with less severe motor difficulties in studies with a clinical sample. Furthermore, the review highlights that social and emotional outcomes for teenagers with mild motor difficulties may be under-recognised.

Recruitment bias may account for the differing perceptions of parents and young people reflected in the qualitative literature. Participants are usually required to 'opt in' to qualitative research because of the nature of data collection and time investment required. Stephenson and Chesson (2008) speculated that the relatively high response rate for their study despite parents having had only fleeting contact with their therapy service several years previously, might reflect parents' desire for professional contact because their children were still experiencing challenges in their everyday lives. By contrast, young people may be motivated to participate in studies by the opportunity to share positive experiences and to meet others who share their diagnosis. Parental consent for young people to participate in research studies is usually required by researchers alongside assent from teenagers themselves. Parents might therefore have discouraged teenagers who were emotionally vulnerable from participating for fear of reminding them of previous negative experiences, thus biasing participant recruitment towards teenagers who were more resilient.

The gender representation in study samples is of note. Studies report a higher prevalence of DCD in boys, with gender ratios of around 2:1 male to female (Lingam et al. 2009). According to these statistics, girls were over-represented in some studies (Cantell, Crawford and Doyle-Baker 2008, Fitzpatrick and Watkinson 2003, Gillberg and Gillberg 1989, Missiuna et al. 2008a, Piek, Baynam and Barrett 2006, Skinner and Piek 2001). It is of interest that more girls were included in studies involving older participants. This suggests that motor difficulties may not be recognised in girls in early childhood, possibly because adults are less likely to notice poor gross motor ability in girls compared to boys or because girls are better than boys at managing their difficulties at school. The findings of studies with a higher representation of girls should therefore be interpreted with caution.

as the girls included in these studies may have more severe difficulties which could result in an over-estimation of the significance of factors identified.

All qualitative studies included in this review were completed within the last 15 years suggesting that only recently has the importance of understanding the perspectives of those affected by DCD/dyspraxia been recognised. Several qualitative studies explored issues from the perspective of parents/carers (Missiuna et al. 2006a, Missiuna et al. 2007, Stephenson and Chesson 2008), perhaps assuming that young people are unable to report their own experience or reflecting the ethical challenges of carrying out research with young people directly. This approach assumes however, that parents are accurate informants on the lived experience of DCD/dyspraxia and risks marginalising the voice of young people themselves. Furthermore, the findings suggest that parents and teenagers differ in their perceptions of the impact of DCD/dyspraxia on teenagers' lives, thus supporting the need for more qualitative research involving young people with DCD/dyspraxia as informants so that matters of importance to teenagers themselves can be identified and explored.

Limitations of the research literature review

Limitations of the literature review described in this section are acknowledged. While a structured approach was taken to identify relevant literature it is possible that some relevant material was missed, including grey literature and studies written in other languages. A narrative approach to the critique and synthesis of available material was adopted; this approach is structured and methodical but uses less explicit and rigorous processes for searching, critically appraising and synthesising the literature than a systematic review (Akobeng 2005). A further limitation of this review is that only one researcher undertook the critical appraisal of material. Despite these limitations however, this literature review has enabled the gathering and synthesis of a large body of relevant literature in order to provide a comprehensive background for understanding current knowledge and highlighting gaps and inconsistencies in the extant literature regarding teenagers with DCD/dyspraxia (Cronin, Ryan and Coughlan 2008).

Section summary

The findings of this review suggest that there is a developmental trajectory for adolescents with DCD/dyspraxia, but that social, behavioural, academic and emotional outcomes cannot be predicted by the profile and severity of a person's movement difficulties in childhood. Follow-up studies and findings from the adult literature suggest that motor difficulties persist in around 50% of young people, and that persistent motor difficulties may be associated with lower IQ and poorer social, behavioural and educational outcomes. Studies further indicate that long term outcomes extend beyond the motor domain and are influenced by a combination of personal and environmental

factors (including gender, attention problems and opportunities for skill development) and the attitude and reaction of others to an individual's skills and performance.

The research raises interesting questions about the group of teenagers identified with movement difficulties in childhood whose motor skills improve by adolescence. Some young people may 'catch up' with their better coordinated peers in some aspects of their development, although this is not the case for all children and improvements do not occur in a homogenous pattern (Cantell, Smyth and Ahonen 2003). Findings from the qualitative literature suggest that even though some adolescents may eventually achieve an acceptable level of motor competence through a process of maturation and practice, many continue to experience academic challenges while previous experiences may result in heightened anxiety about the possibility of future failure, embarrassment and humiliation. Doubts about their competence affect teenagers' choice of pastimes, educational choices and employment options, and might therefore have long term consequences for an individual's health, economic and psychosocial well-being.

The findings of this review indicate that parents and young people differ in their perceptions of the social and emotional impact of DCD/dyspraxia during adolescence. Parents painted a rather gloomy picture. Although less concerned about their child's motor difficulties as they grew older parents highlighted concerns about their social vulnerability, mental health and academic underachievement. By contrast, studies in which people with DCD/dyspraxia were themselves the respondents were more optimistic. There was a sense that increased control and choice over activities, friendship groups and the context in which activities took place helped to reduce teenagers' sense of difference and isolation. Furthermore, teenagers and young adults with DCD/dyspraxia appeared more accepting of their uniqueness as they grew older and felt that their peers appreciated, rather than dismissed their differences.

This section explored the quantitative and qualitative literature, providing evidence that for many young people the impact of DCD/dyspraxia on daily life continues beyond childhood into adolescence. With this in mind, the following section explores the support that is available for teenagers with DCD/dyspraxia from occupational therapists, the allied health professionals who work most frequently with this client group (Forsyth et al. 2008).

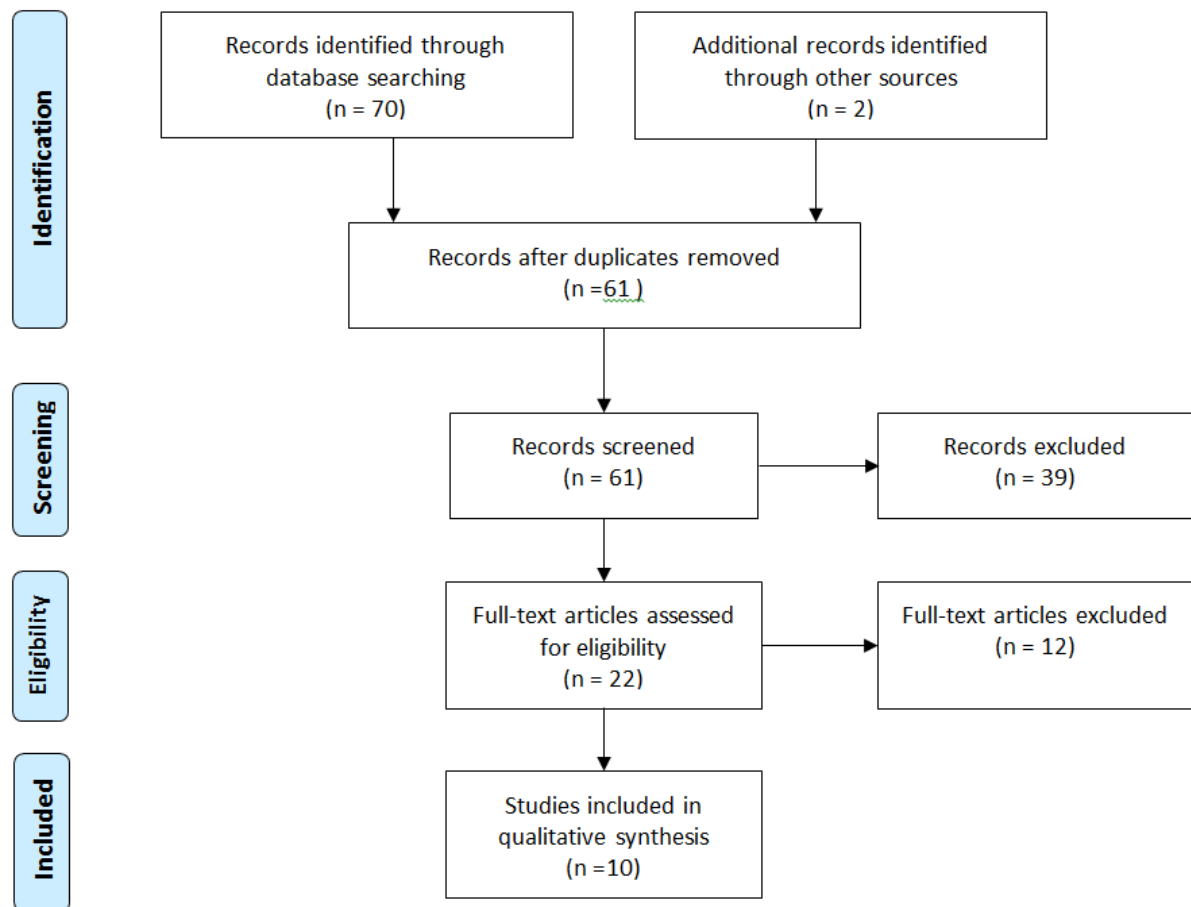
How easy is it for teenagers with DCD/dyspraxia to access occupational therapy services?

This section examines relevant articles and policy documents pertaining to the provision of occupational therapy for young people with DCD/dyspraxia and qualitative literature exploring parents'/carers' experience of accessing occupational therapy services. Policy documents were

included because they illustrate the context in which services for people with DCD/dyspraxia are delivered and experienced by teenagers and their parents. The review focuses on occupational therapy as occupational therapists play a significant role in diagnosing and supporting young people affected by the condition (College of Occupational Therapists 2012, College of Occupational Therapists 2013b, Missiuna et al. 2008b). Furthermore, occupational therapists are the allied health professionals most likely to be working with young people with DCD/dyspraxia (Forsyth et al. 2008). As an occupational therapist I am also interested in examining the type of services offered in the UK, and parents'/carers' experience of accessing these.

A systematic search of five relevant databases (Amed, Cinahl, Medline, PsychINFO and Academic Search Complete) was carried out using the search terms 'developmental coordination disorder' or 'developmental co-ordination disorder' with 'service model', 'guidelines', 'pathway,' 'protocol', 'service' and 'occupational therapy'. The term developmental coordination disorder was chosen in preference to dyspraxia as it is most commonly used by occupational therapists to describe the condition. The search revealed 70 possible papers, 61 after duplicates were removed. Two additional papers were identified through other sources. 39 records were excluded following screening of abstracts for eligibility. 22 full text articles were retrieved and assessed for inclusion. 12 were excluded (reasons for exclusion are provided in Appendix B), leaving 10 eligible studies. Only four qualitative UK studies describing parents'/carers'/teenagers' experience of accessing occupational therapy services in the UK were identified. A further four Canadian qualitative research papers were identified (two of which report different findings from the same study); these were included in the review as their findings were similar to and therefore enhance understanding of parents' experience of accessing occupational therapy offered by the UK studies.

Figure 4: Flow of information through difference phases of the systematic review “How easy is it for teenagers with DCD/dyspraxia to access occupational therapy services?”



An internet and hand search for occupational therapy research, policy and practice documents published since 2003 was also undertaken. Documents published since 2003 were chosen to capture current practice while documents relating only to children under 12 years of age and those not relating to DCD were excluded. Policy documents for services outside the UK were also excluded.

Table 6 details the documents and papers that were included in this review. When a document or research paper relates to a Scottish population this is highlighted as the law and funding arrangements for Scotland are different from those for services in England and Wales and might therefore affect teenagers’ experience of accessing occupational therapy. A critical appraisal of included papers is provided in Appendix C.

Table 6: Included articles and documents regarding access to occupational therapy for teenagers with DCD/dyspraxia

Document Title	Type of document/research	Country of origin
Camden, C., Wilson, B., Kirby, A., Sugden, D., and Missiuna, C. (2015) 'Best Practice Principles for Management of Children with Developmental Coordination Disorder (DCD): Results of a Scoping Review'. <i>Child: Care, Health and Development</i> 41 (1), 147-159	Scoping review	UK
College of Occupational Therapists and National Association of Paediatric Occupational Therapists (2003) <i>"Doubly Disadvantaged" - Report of a Survey on Waiting Lists and Waiting Times for Occupational Therapy Services for Children with Developmental Coordination Disorder</i> . London: College of Occupational Therapists and National Association of Paediatric Occupational Therapists	Audit report of OT provision for children with DCD in the UK	UK
College of Occupational Therapists (2012) <i>Developmental Coordination Disorder: Fact Sheet</i> London: College of Occupational Therapists	OT evidence paper	UK
College of Occupational Therapists (2013) <i>Access to Occupational Therapy for Children and Young People with Developmental Coordination Disorder: Position Statement</i> London: College of Occupational Therapists	Position Statement	UK
College of Occupational Therapists (2013) <i>Diagnosis of Developmental Coordination Disorder: Practice Briefing</i> London: College of Occupational Therapists	Practice Briefing	UK
Forsyth, K., Maciver, D., Howden, S., Owen, C., and Shepherd, C. (2008) 'Developmental Coordination Disorder: A Synthesis of Evidence to Underpin an Allied Health Professions' Framework'. <i>International Journal of Disability, Development and Education</i> 55 (2), 153-172	Report of the development of an AHP framework for young people with DCD	Scotland
Lingam, R., P., Novak, C., Emond, A., and Coad, J., E. (2014) 'The Importance of Identity and Empowerment to Teenagers with Developmental Co-Ordination Disorder'. <i>Child: Care, Health & Development</i> 40 (3), 309-318	Qualitative study	UK
Maciver, D., Owen, C., Flannery, K., Forsyth, K., Howden, S., Shepherd, C., and Rush, R. (2011) 'Services for Children with Developmental Co-Ordination Disorder: The Experiences of Parents'. <i>Child: Care, Health & Development</i> 37 (3), 422-429	Qualitative study	Scotland
Missiuna, C., Moll, S., King, S., Law, M., and King, G. (2006) '"Missed and Misunderstood": Children with Coordination Difficulties in the School System'. <i>International Journal of Special Education</i> 21 (1), 53-67	Qualitative study	Canada
Missiuna, C., Moll, S., Law, M., King, S., and King, G. (2006) 'Mysteries and Mazes: Parents' Experiences of Children with Developmental Coordination Disorder'. <i>Canadian Journal of Occupational Therapy</i> 73 (1), 7	Qualitative study	Canada

NHS Quality Improvement Scotland (2008) <i>"I Still can't Tie My Shoe Laces": NHS Quality Improvement Scotland Response to Developmental Coordination Disorder. A Review of Evidence and Models of Practice Employed by Allied Health Professionals in Scotland.</i> Scotland: NHS Quality Improvement Scotland	Report of the development of an AHP framework for young people with DCD	Scotland
Novak, C., Lingam, R., Coad, J., and Emond, A. (2012) 'Providing More Scaffolding': Parenting a Child with Developmental Co-Ordination Disorder, a Hidden Disability'. <i>Child: Care, Health and Development</i> 38 (6), 829-835	Qualitative study	UK
Rodger, S. and Mandich, A. (2005) 'Getting the Run Around: Accessing Services for Children with Developmental Co-Ordination Disorder'. <i>Child: Care, Health & Development</i> 31 (4), 449-457	Qualitative study	Canada
Salmon, G., Cleave, H., and Samuel, C. (2006) 'Development of Multi-Agency Referral Pathways for Attention-Deficit Hyperactivity Disorder, Developmental Coordination Disorder and Autistic Spectrum Disorders: Reflections on the Process and Suggestions for New Ways of Working'. <i>Clinical Child Psychology and Psychiatry</i> 11 (1), 63-81	Service audit report	UK
Stephenson, E. A. and Chesson, R. A. (2008) 'Always the Guiding Hand': Parents' Accounts of the Long-Term Implications of Developmental Co-Ordination Disorder for their Children and Families'. <i>Child: Care, Health and Development</i> 34 (3), 335-343	Qualitative study	Scotland

Occupational therapy for teenagers with DCD/dyspraxia

The College of Occupational Therapists (COT) supports the right of young people with DCD aged 0-18 years to receive timely support and intervention to enable them to live more productive and enjoyable lives and to become independent in the things they need or want to do (College of Occupational Therapists 2013a). Occupational therapists contribute to the diagnosis of DCD by assessing a young person's motor coordination and are particularly skilled at determining whether an individual meets Criterion A of the DSM-V diagnostic criteria when standardised tests do not include norms for older children (College of Occupational Therapists 2013b). Occupational therapists are also skilled in assessing the impact of motor difficulties on everyday function, taking into account the young person's age (College of Occupational Therapists 2013a). COT states that occupational therapy can help to minimise the risk of long term negative outcomes by providing early and appropriate support and intervention, yet a survey of occupational therapy provision for young people with DCD in the UK found that children with DCD were a lower priority than children with more severe impairments in 30% of responding NHS trusts and that the mean waiting time for an assessment for young people with DCD was 46 weeks (College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003). The authors argue that young

people with DCD are 'doubly disadvantaged' because of the impact of their motor difficulties on daily life activities and their difficulty accessing occupational therapy in a timely manner. Furthermore, the survey reported that many services restrict access to occupational therapy by age or diagnosis, implying that young people with coordination difficulties may be unable to access occupational therapy because they are too old.

The review of policy documents indicates that younger children with DCD/dyspraxia are the main focus for occupational therapy. Although an explanation for this age bias is not articulated, the justification that early intervention is essential to improving outcomes for people with coordination difficulties is implied (College of Occupational Therapists 2013a). It is interesting to note that the multi-agency pathway described by Salmon et al (2006) for autism includes support for students of secondary school age, whereas the DCD pathway only refers to young people at primary school, suggesting that older children with DCD might have less opportunity to access help and support than older children with other developmental conditions. A similar age bias is exposed by the methods used to examine models of practice for children with DCD employed by allied health professionals in Scotland. Focus groups were held with parents and young people aged 6-8 years and 9-12 years who were receiving therapy interventions (NHS Quality Improvement Scotland 2008). Although not explicitly stated it is implied that these ages were chosen to represent the age of children most likely to access therapy services in Scotland.

The authors of a scoping review of best practice principles for the management of children with DCD acknowledge the challenge of providing effective therapy services for young people with DCD when resources are limited (Camden et al. 2014). They argue for a reorganisation of health services and the development of innovative partnership approaches to foster capacity-building amongst teachers and community groups alongside the identification of clear pathways to ensure timely access to diagnosis, assessment and intervention for young people with coordination difficulties who require specialist support. Similar recommendations were made by Quality Improvement Scotland (NHS Quality Improvement Scotland 2008) who organized key themes and principles around the child and family's journey from identification, assessment and diagnosis, through intervention to discharge. Whilst the recommendations of both reviews may be applied to teenagers with DCD/dyspraxia, this is not specifically stated and advice about how recommendations might be implemented to meet the developmental and contextual challenges experienced by adolescents with DCD is not provided.

The review indicates that teenagers with DCD/dyspraxia are largely absent in occupational therapy policies, guidelines, pathways and protocols. Most documents acknowledge the increased risk of negative outcomes for young people with coordination disorders as they get older but focus on early

intervention to minimise the risk. Young people whose coordination and associated difficulties continue into adolescence, or whose difficulties are not identified until they reach secondary school are not addressed. Moreover, limiting service provision by age and failure to identify clear pathways and support for teenagers with DCD/dyspraxia when there is clear evidence that difficulties persist into adolescence and can have a serious negative impact on life outcomes, is unfair and adds to the disadvantage already experienced by teenagers with DCD/dyspraxia because of their coordination and associated difficulties.

Parents'/carers' experience of accessing occupational therapy for their teenage children

None of the qualitative studies included in this review focus specifically on parents'/carers' experience of trying to access services for their teenage children; furthermore, while several of the studies were conducted by occupational therapy researchers the findings relate to the experience of accessing services generally, and not just occupational therapy. Despite these limitations all studies offer insights of relevance to the current study. Findings are grouped into five broad themes: 1) struggling to get concerns acknowledged 2) fighting to access services 3) coordination of services 4) parents as advocates and 5) receiving therapy. Each of these themes will be discussed in turn. For ease of reading the term 'parents' refers to both parents and carers in this section.

Struggling to get concerns acknowledged

The trivialisation or dismissal of parents' early concerns by professionals including health visitors and nursery teachers emerged as a strong theme (Missiuna et al. 2006b, Novak et al. 2012, Rodger and Mandich 2005). Parents felt that health and education professionals lacked knowledge and understanding of DCD/dyspraxia, leading to inappropriate reassurance that their child was developing typically and/or delays in making onward referrals for further investigation (Maciver et al. 2011, Rodger and Mandich 2005). Parents expressed frustration that some teachers did not recognise their child's difficulties because they did not cause problems in the classroom, unlike children with behavioural difficulties whose needs were more obvious (Maciver et al. 2011).

Fighting to access services

Parents felt they had to fight to secure an assessment, diagnosis and help for their children (Maciver et al. 2011, Missiuna et al. 2006b, Rodger and Mandich 2005, Stephenson and Chesson 2008) and had to navigate their way through many different professionals before receiving the support their children needed (Missiuna et al. 2006b, Novak et al. 2012). They were frustrated that many professionals seemed unaware of how other services could help as pathways were unclear and inconsistent (Maciver et al. 2011, Rodger and Mandich 2005). There was a perception that professionals acted as gatekeepers rather than as advocates who wanted to secure the most appropriate service for a child (Novak et al. 2012). Parents were angry and frustrated at the waiting

time for occupational therapy (Maciver et al. 2011, Missiuna et al. 2006b) and there was confusion about the variation in provision between localities (Rodger and Mandich 2005). Parents were concerned that children with DCD/dyspraxia were seen as a lower priority than children with more severe or obvious impairments, a concern supported by the findings of a national audit of occupational therapy provision (College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003).

Coordination of services

The lack of service coordination emerged as a strong theme; parents were concerned about poor communication between health professionals and between health and education (Maciver et al. 2011, Rodger and Mandich 2005). Parents reported a discontinuity of care and a lack of planning ahead which left them feeling unsupported at significant times such as the transition to secondary school (Maciver et al. 2011, Rodger and Mandich 2005). Parents were concerned about discrepancies in professional knowledge which led to mixed messages and missed opportunities for support (Maciver et al. 2011, Novak et al. 2012). Parents felt that they had to take on the role of coordinating information-sharing about their child (Novak et al. 2012).

Parents as advocates

There was a realisation and acceptance amongst many parents that they needed to advocate on behalf of their child to access help and support (Novak et al. 2012, Rodger and Mandich 2005). Some parents, however, lacked the skills and knowledge to demand support for their child and had lower expectations or were less motivated to follow professional guidance (Novak et al. 2012). There was a sense of frustration that professionals were unable or unwilling to direct them to alternative sources of support and that parents had to seek out information for themselves (Novak et al. 2012). Furthermore, when DCD/dyspraxia was diagnosed in adolescence, parents had to rethink how to parent and support their child whilst at the same time struggling with other issues associated with parenting a teenager (Novak et al. 2012).

Receiving therapy

Most parents were recruited to studies because their children were receiving or had received therapy services. Parents experienced a sense of relief that their child's needs were recognised and reported that therapists helped them to understand their child and had improved their self-esteem by helping them to acquire skills (Maciver et al. 2011, Missiuna et al. 2006b). Parents particularly cherished therapists who prioritised the needs of the child and family, focusing on meaningful activities rather than improving body functions (Maciver et al. 2011). Although parents valued occupational therapy and felt that it was worth waiting for, there was a sense of abandonment when

intervention ended and of frustration that it was difficult to access on-going support (Maciver et al. 2011, Missiuna et al. 2006b).

The young people's perspective

Only two studies asked young people about their experience of accessing therapy services. Children aged 6-12 years in the study by Quality Improvement Scotland (2008) said they found therapy fun, although the first session was a bit embarrassing or upsetting. They were keen to be better at doing things for themselves, but didn't always see a connection between their personal goals and therapy sessions. Teenagers in the study by Lingam et al (2014) reported that occupational therapists had helped them to understand their difficulties better which boosted their confidence. They appreciated attending therapy groups because this gave them the opportunity to meet others like themselves and reduced their sense of isolation. Occupational therapy had helped them to develop skills and gave them a sense of belonging.

Limitations of the review of policy documents and research literature in this section

Despite the search strategy adopted for the policy review it is possible that some relevant material regarding occupational therapy service delivery models/protocols/guidelines may have been missed, in particular those developed by individual therapy services. These might have revealed more details about the reality of services offered (or not offered) to teenagers with DCD/dyspraxia in the UK. None of the documents reviewed specifically mention pathways or protocols for teenagers with, or suspected of having DCD/dyspraxia. While it is assumed that the service models described are applicable to adolescents, it is unknown whether teenagers are in fact able to access occupational therapy services or whether the age limitations described in the 'Doubly Disadvantaged' report (College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003) still apply.

There were some methodological weaknesses in the qualitative studies included in this review. Many drew participants from a clinical population and the researchers may have had previous professional contact with the parents that could influence the study findings (Missiuna et al. 2006b, Rodger and Mandich 2005, Stephenson and Chesson 2008). Furthermore, in many cases the joint role of therapist/researcher on the study findings and conclusions was not discussed. Although occupational therapists are the allied health professionals most likely to be involved with children with DCD/dyspraxia (Forsyth et al. 2008) in most studies it is difficult to identify whether parents' experiences related to their experience of accessing occupational therapy or another health service. Most parents had accessed therapy services for their younger children; issues related to accessing services for young people once they reached adolescence were not explored. In only one study

(Novak et al. 2012) was the issue of having to reconsider parenting approaches because of the late diagnosis of DCD/dyspraxia during adolescence mentioned. Only two papers reported young people's experiences of accessing therapy services. However, young people were mostly positive about their experience of occupational therapy once they had access to the service.

Chapter summary

This chapter provides an up to date synthesis of research literature examining what it is like to be a teenager with DCD/dyspraxia in the UK. It demonstrates that for many, coordination difficulties that were evident in childhood persist into adolescence and can have serious secondary consequences for the development of life skills, academic attainment, social participation and emotional well-being. A small number of longitudinal studies focus on quantitative measures of motor, cognitive and social functioning. Methodological weaknesses and differences in the way in which participants were recruited however, make it difficult to compare findings and to draw conclusions about the long term impact of DCD/dyspraxia. Only two studies exploring the experience of living with DCD/dyspraxia from the perspective of adolescents themselves were identified, one of which reports preliminary findings from this study (Lingam et al. 2014, Payne et al. 2013). Other qualitative studies used parents as informants (Missiuna et al. 2007, Stephenson and Chesson 2008) or asked adults to reflect back on their adolescent years (Fitzpatrick and Watkinson 2003, Missiuna et al. 2008a). Parents' perspectives present a particularly strong message about the range and quality of services received. There is therefore a need to explore further the challenges experienced by adolescents with DCD/dyspraxia from their own perspective and to consider how these experiences may contribute to their success or difficulties in later life. The findings of this review suggest that young people with DCD/dyspraxia benefit from occupational therapy (Blank et al. 2012), yet a review of policy documents and the qualitative literature indicates that parents find it difficult to access this. Moreover, lack of clear pathways and poor communication between occupational therapists and other professionals may reduce the efficacy of support offered and result in an inefficient use of scant resources; these process issues may impact on outcomes for young people with DCD/dyspraxia.

Chapter Conclusion

The conclusion of this review is that teenagers with DCD/dyspraxia are a neglected population in both research and clinical practice. Moreover, quantitative literature reflects professional concerns and interests, while the qualitative literature is strongly biased towards parental perspectives rather than the perceptions of teenagers living with DCD/dyspraxia themselves. To address these concerns the following research question was developed:

- How is life experienced by adolescents with DCD/dyspraxia from their own contemporaneous perspective?

In order to answer this question and to ensure that the study was relevant to teenagers with DCD/dyspraxia and would offer meaningful outcomes for research and practice, a Reference Group of older teenagers and young adults was established. The rationale for involvement of a Reference Group and its role in the study are described in the next chapter.

Chapter 3

Service user involvement in the research

Chapter 3: User Involvement

The preceding chapter presented the findings of a review of literature and policy documents, demonstrating current knowledge about how life is experienced by teenagers with DCD/dyspraxia and their access to occupational therapy. It identified a deficit in knowledge and outlined the need to provide further insight into the lived experience of teenagers with DCD/dyspraxia from their own contemporaneous perspective. As an occupational therapist who believes in working in partnership with young people and families, it was important to me that people with DCD/dyspraxia should be involved in this project as co-researchers from the outset. This chapter therefore focuses on the rationale for, and role of a Research Reference Group on the study. The impact of the Reference Group on the study is explored later in Chapter 8.

This chapter begins by describing the contemporary context for involving service users in research. It outlines various models of user involvement and explores user involvement in occupational therapy research and in qualitative studies. A rationale for involving a Research Reference Group is offered along with a description of the method of involvement and role of the group.

Context

The principles and value of involving service users in health and social care research are widely acknowledged in the literature and in UK research policy. In this context the term ‘service users’ includes patients, carers, people who use health and social care services, potential users of health and social care services, and organisations that represent people who use these services. The importance of patient and public involvement is emphasised by the Department of Health in its research strategy (Department of Health 2006) which also, through the National Institute of Health Research, funds INVOLVE, a national advisory group that supports greater public involvement in NHS, public health and social care research. The high priority of involvement of service users and members of the public in research is also evidenced by the requirement of many research funders for user involvement in research projects (Beresford 2007). Detailing how users will be involved in projects is a requisite for all researchers applying for NHS research ethical approval, regardless of their disciplinary background or methodological stance (Wright et al. 2010).

User involvement is a core component of good research practice for all forms of research (Wright et al. 2010) and an increasing number of research papers address the issue of service user involvement in their study. There is also a growing body of literature, debate and discussion regarding user involvement in the research process (Chambers, Clarke and Cooke 2009). INVOLVE defines public involvement in research as “research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.” (INVOLVE 2012a) yet confusion remains regarding what

patient/public/user involvement in research actually means. A study by Thompson et al (2009) into researchers' attitudes towards public involvement in health research identified many varied conceptual perspectives on public involvement, from developing research 'partnerships', to 'offering information' to the public about research and involvement through 'participation in a clinical trial' (p213). Despite these varying constructs, a range of moral, political and consequentialist reasons for involving the public in research were identified. However, the authors suggest that feelings of apprehension expressed by a number of participants indicate a continuing need for education, training and discussion to increase understanding of the practicalities and realities of public involvement in health research.

User involvement in research is a relatively recent innovation. Early policies for involving users in research were based on models that conceptualized the service user as a consumer of health services (Wright et al. 2007). According to this model the views of service users are sought with the aim of improving the research "product", for example service users might be invited to sit on an advisory panel or asked to comment on project proposals. The role of users was therefore *added on* to an existing research process. Beresford (2003) argued that this model of user involvement does little to alter the distribution of power between researchers and services users as the responsibility for making decisions about the research remains with professional researchers. This approach has led to frustration amongst service users who report little change to the research process for much effort on their part, and a feeling that their involvement is tokenistic with minimal influence over the focus of the research or its outcomes (Beresford 2003).

By contrast, 'emancipatory research' or 'survivor research' is a model of user involvement driven by service users, service user organisations and service user researchers. Such research has its origins in the disabled people's movement and has a commitment to equality and making change at a personal and a social/political level for service users. Informed by feminist, black and educational/developmental research approaches, emancipatory research shifts the balance from *"increasing professional knowledge, power and control to the liberation and emancipation of service users/research participants"* (Beresford 2007). Such research values what service users know about the "lived experience" above the knowledge claims of academics and professional researchers. These beliefs are consistent with the phenomenological stance adopted for the current study.

The involvement of service users in research is informed by the democratic principles of citizenship, transparency and accountability (Staley 2009); yet while user involvement is now embedded as a good practice principle and a policy requirement in health and social care research, there is a concern to ensure involvement is meaningful rather than tokenistic (McKevitt, Fudge and Wolfe

2010). Being clear about *why* service users should be involved in research helps to ensure that their involvement has a positive impact on the research design, conduct and dissemination.

Why involve users in research?

It is argued that involving service users in research can enhance a study's quality and relevance, leads to more ethical research and can bring direct benefits to service users. Justification for the involvement of service users in research is explored in this section.

It is claimed that user involvement can enhance a study's relevance and quality by helping to ensure that the research question addresses the public's interests and concerns as well as those of the researcher (McKevitt, Fudge and Wolfe 2010). By contrast, failure to involve users in prioritising topics for research may mean that important areas of inquiry remain unrecognised and unsupported (Wright et al. 2007). Evidence suggests that involving services users in research can enhance the collection of relevant and useful data as studies indicate that participants are more likely to give fuller and open responses to questions that have been developed with the involvement of people who have similar experiences (Beresford 2007). Participants in a study examining the personal costs of stroke for example reported *"feeling at greater ease being interviewed by someone who had been in a similar situation to themselves"* (McKevitt, Fudge and Wolfe 2010). Thus user involvement can help to ensure a study's relevance and enhance quality through the collection of meaningful data.

There are practical benefits to involving service users in research as they can facilitate the recruitment of participants by identifying recruitment methods that lead to better service user engagement. Service user input into a clinical trial for the treatment for prostate cancer for example, led to significant changes in the way that potential participants were approached. The process of informed consent was improved, making it easier for people to understand the research and its possible risks, resulting in participation rates improving from 40% of those approached to 70% (National Cancer Research Institute 2012). Accessing hard to reach and marginalised groups is another benefit of service user involvement (INVOLVE 2012a). Beresford (2007) argues that increasing the diversity of users involved in research is important as a way of *"casting light on existing exclusions and marginalisation"* which can then help to increase understanding of health inequalities so that they can be addressed (p306). Staley and Minogue (2006) further argue that user-led research helps to promote cultural values by reducing the social stigma and marginalisation experienced by some service users, especially those with mental health issues.

Another argument for user involvement is that it leads to more ethical research. Consultation with patients, carers and patient organisations can help to define what is ethically acceptable in areas that are potentially risky or controversial (INVOLVE 2012b). For example service users can help to

ensure that potential risks are explained so that they can be understood thereby ensuring that consent to participate is truly informed. Staley and Minogue (2006) also argue that taking part in research that is relevant and likely to benefit patients and potential service users is a more valuable, respectful and therefore ethical use of participants' time.

There is growing evidence that being involved in research brings personal benefits to those involved (INVOLVE 2010). Gains include feeling listened to, meeting others with similar experiences, and increased knowledge and understanding of their own experience (Fudge et al. 2008). Additional personal and group benefits include bringing something positive to the experience of living with a major illness; being part of a group where their experience of illness is both understood and accepted; and having the opportunity to pursue a new purposeful activity (Cotterell et al. 2010).

A final benefit of involving service users in research is that it may lead to the wider dissemination of findings. Staley and Minogue (2006) argue that service user researchers have a strong commitment to sharing their findings with audiences including service users and carers. User involvement therefore can lead to research being shared beyond the academic and research audiences typically targeted by professional researchers.

The involvement of service users in health research is therefore a political priority and is increasingly acknowledged as good practice. It is however a complex process and careful planning is required to ensure that user involvement is meaningful and ethical, rather than tokenistic and disempowering. The challenges to meaningful and ethical involvement of service users in research are explored in the following section.

Challenges to involving users in health research

The involvement of patients and members of the public in research is not without challenge and controversy. A conference held by the Social Research Association in 2005 entitled "Necessity or Nuisance? The Role of Non-researchers in Research" prompted much debate. Subsequent reporting of the conference promoted the view that user involvement was a significant obstacle to the rigour and reliability of research as the closeness of user researchers to the problem being studied introduced weaknesses that could affect the reliability and objectivity of the knowledge generated (Beresford 2007). Beresford (2007) challenged the assumption that the greater the distance between direct experience and its interpretation, the more reliable it is, and questioned why academics/researchers were often attributed higher knowledge status than service users with experiential knowledge. In support of this perspective, Fieldhouse (2012) argued that the involvement of mental health service users as co-researchers actually helped to mitigate bias that might be introduced by the involvement of professional researchers/clinicians in his study. It has

been suggested that scepticism by academics about the value of user-led research might lead to the tokenistic involvement of service users in research, leaving them feeling unsupported and unable to fulfil their role (Rose 2003). Beresford argues that the continuing undercurrent of tension between negative attitudes towards user involvement and the increasing requirement to involve service users in health and social care research is a challenge that needs to be acknowledged and subjected to academic and research debate (Beresford 2007).

User involvement in research has been criticised for not being representative of all service users, a situation which is compounded by the tendency for health professionals to select those who are 'well behaved' and likely to support the researchers' viewpoints (Wright et al. 2007). Increasing diversity and including groups whose voices are seldom heard in health research is an ongoing challenge for researchers. Groups who are often overlooked or who are not given the opportunity to be involved in research include disabled people; certain age groups (including young people and older people); lesbian, gay, bisexual and transgender people; black and ethnic minority groups; and people from different faith communities (INVOLVE 2012c). Strategies to promote inclusion and diversity of user participation include building relationships between the researcher and service users and considering alternative forms of involvement such as online forums. INVOLVE also suggest increasing the diversity of users in research by considering and accommodating user groups' needs, abilities, interests and availability.

A range of practical challenges to the involvement of service users have been identified. Wright et al (2010) caution that there is a need to consider *"pragmatic issues in order to ensure that effective involvement practice and the quality of research are not compromised"* (p361). An example of the identification and management of practical challenges can be found in the study by McKevitt (2010): users in this project had problems with mobility, speech and cognition following a stroke so researchers had to allocate extra time for planning and for carrying out user involvement activities. They also needed to consider the physical accessibility of the research environment.

Meaningful and effective user involvement in research has financial implications (Wright et al. 2007). Building in costs for translators, travel and service user meetings for example, add to project costs and need to be included in research budgets. It is however, difficult to obtain funding to involve users in the initial development stages of a project which may limit opportunities for users to help develop research questions and to contribute in the early stages of project design (Thompson et al. 2009). Building in time for effective user involvement is another challenge. A study by Coad et al (2012) needed extra time to provide training and mentoring for inexperienced service users who took on the role of researchers (referred to as 'user researchers') to ensure rigour of the research. A

project plan may also be delayed if, for example service users require clearance from the Disclosure and Barring Service before they can be involved in collecting data, or if a meeting has to be rescheduled because users are unable to attend. This is a challenge for researchers who are often working to tightly defined project deadlines (Thompson et al. 2009).

There are ethical challenges to the involvement of patients and service users in research. Patient confidentiality may be compromised if users have access to patient data through their participation in a study (Wright et al. 2007). This issue was noted by Coad et al (2012) who provided training to raise awareness of confidentiality and handling of sensitive information among user researchers. Staley and Minogue (2006) recommend that researchers consider how to support service users who may become distressed if their involvement causes them to relive their own painful or emotional experiences. They also express frustration that while ethical review bodies want to know how services users will contribute to the research in their application process, their policy and practice *“does little to promote user involvement and in some instances has proved to be a barrier”* (p97). In particular they argue that the complex application and ethical approval processes is intimidating and discouraging to service user researchers. They cite examples of research ethics committees that didn't seem convinced of the value of service user involvement or who were over-protective and effectively denied patients and service users the opportunity to participate in research that concerned them.

Involving young people as researchers presents additional challenges, two of which were explored by Kellett (2010). Firstly, sceptics argue that children do not have the competence to undertake research because of their age. This argument is based on developmental theories, but doesn't account for a young person's social experience which, Kellett argues, is a more reliable marker of a person's maturity and their competence to participate in research. Secondly, it has been argued that children lack research knowledge and skills. Kellett contends, however, that it is not their age, but a lack of training in research skills that presents a barrier; moreover, adults also lack research skills unless they have received appropriate training. Similar challenges have been raised regarding the involvement of people with learning disabilities in research. Tuffrey-Wijne and Butler (2010) describe the challenge of balancing academic rigour in the research process with the meaningful and appropriate involvement of users with learning disabilities. They acknowledged that the power in their study remained with the non-learning disabled researchers because of the complexity of abstracting themes and integrating theory into their findings, but argued that the involvement of researchers with learning disabilities was both crucial and valuable to their project. They concluded that it was important to be *“realistic and upfront about the power imbalances within research*

teams” when involving service users with learning disabilities in research (Tuffrey-Wijne and Butler 2010).

Limited evidence of the impact of user involvement in research is another challenge (Beresford 2007) that has been addressed more recently in the literature. In 2010 White et al published guidance for assessing the quality and impact of user involvement in research. This includes considering whether the rationale for involving users has been clearly demonstrated, the appropriateness of the level of user involvement, the recruitment strategy and the attention given to ethical considerations of user involvement in the research. The impact of user involvement in research was also evidenced in a report published by the National Cancer Research Network (National Cancer Research Institute 2012). The report gives five examples of studies that illustrate how patient and public involvement has made a difference to cancer research. The impact of user involvement on the current study is explored in Chapter 8.

Models of user involvement

Several models for the involvement of service users in health research have evolved. Early models of user involvement (or participation) were hierarchical and typically represented as a ladder, for example Arnstein’s Ladder of Citizen Engagement (Tritter and McCallum 2006) and Hart’s Model of Children’s’ Participation (Fraser et al. 2004). Such models have been criticized for being too simplistic and embracing user control as the pinnacle of involvement without considering the processes and appropriateness of user involvement in different contexts (Tritter and McCallum 2006).

An alternative model of user involvement developed by INVOLVE (2012a) includes three (overlapping) categories: **Consultation**, where research is typically initiated by researchers but the views of service users are taken to inform the project; **collaborative research** where service users/ organisations work in partnership with professional researchers; and **user-controlled research** where the locus of power, initiative and decision-making lies with service users rather than professional researchers. INVOLVE acknowledge that service users may be involved in different stages of a research project at different levels according to the type and aims of the study. McKevitt et al (2010) propose an alternative conceptual framework of public involvement in which user involvement is regarded as a dynamic process where the contributions of professionals and service users shift *“throughout the process according to the tasks at hand and the available level of skills”* (p93). They argue for thinking of user involvement as phenomenon where consideration is given to *“what kinds of user involvement are being constructed as researchers and lay people put involvement into practice”* (p93). The model of user involvement chosen for this study is described later in this section.

User involvement in Occupational Therapy research

A key concept linking occupational therapy and user involvement in research is client-centred practice. Client-centred practice is *“characterized by collaborative and partnership approaches to practice that encourage client autonomy, choice and control, respect for clients’ abilities and support for their rights to enact these choices”* (Hammell 2001). Client-centred practice, in which the voice of the service user is listened to and valued at all stages of the therapeutic process is a core philosophy of the profession, embedded in the College of Occupational Therapists Code of Ethics and Professional Conduct (College of Occupational Therapists 2010). There are clear parallels between client-centred practice and the concept of user-led research in which people are involved throughout the research process from defining the problem, to determining the research question, planning and carrying out data collection and analysing and sharing the results.

One example of a user-led research approach adopted by occupational therapy researchers and others that has strong parallels to client centred practice is participatory action research (PAR). Here the research process is controlled by a group of people who participate directly to examine current activity in order to change and improve it. Letts (2003) illustrates the conceptual links between PAR and client-centred practice by describing a number of PAR projects with occupational therapy clients as participants. She reflects on the equal value placed on the expertise of all partners (i.e. clients/participants and therapists/researchers) in both processes. Kramer-Roy (2012) concurs, concluding that the successful outcome of both PAR and occupational therapy depend on the researcher/therapist’s openness to learn from their partners rather than viewing themselves as the “expert”.

Despite the increasing political and policy focus on user involvement in research and the emphasis on collaboration and client-centre practice in occupational therapy, there is a disappointing lack of evidence of user involvement in occupational therapy research. Only three of the 43 research papers (Ball and Shanks 2012, Fieldhouse and Onyett 2012, Kramer-Roy 2012) and none of the critical reviews published in the British Journal of Occupational Therapy during 2012 explicitly mention user involvement in the study other than as research participants. Wright and Rowe (2005) noted a similar lack of involvement of service users in the design, implementation and evaluation of occupational therapy service delivery, arguing that user involvement was inhibited by *“professional insecurity and role uncertainty”* (p45). This, they argue, is of concern in a profession that claims to have collaboration and partnership working at its core.

User involvement in qualitative studies

User involvement in research would seem to have a natural synergy with qualitative research approaches that prioritise the voice of the user and seek to understand phenomena from participants' perspective. There are many examples of service user involvement in designing (Ong and Hooper 2003, Staniszewska et al. 2007), undertaking (Tuffrey-Wijne and Butler 2010) and sharing the findings of qualitative research (for example at the biennial INVOLVE conference). It has been argued that service user involvement in qualitative research brings particular benefits, particularly in relation to data collection. Studies indicate that participants are likely to be more open in focus groups or interviews that are facilitated by service users thereby enhancing the depth and richness of data collected (Staley and Minogue 2006). Participants who were interviewed by a service user in a study exploring satisfaction with mental health services, for example, reported positive aspects such as feeling special and enjoying an atmosphere of comradeship with the service user researcher. However, participants also expressed anxiety about confidentiality and sometimes doubted the competence of service user researchers, especially when too much personal information was shared by the researcher (Bengtsson-Tops and Svensson 2010).

Involving service users in the analysis of qualitative findings and generation of knowledge is challenging, and qualitative studies have been criticised for avoiding the challenge by viewing findings through the lens of a professional researcher (Hammell 2001). One argument against the involvement of service users in qualitative data analysis is the complexity of the analytical process. Blackburn et al (2010) however argue that while service users are likely to be novice researchers, 'professional' researchers also have to learn research skills. Indeed, a growing number of projects include training to enable service users to engage in qualitative data analysis including young people (Fleming, Goodman Chong and Skinner 2009) and people with learning disabilities (Tuffrey-Wijne and Butler 2010).

Gillard et al (2010) explored the impact of involving mental health services user researchers in research into the experiences of detained psychiatric patients, comparing the way in which service user researchers and university researchers conducted and analysed qualitative interviews. Their results suggested the possibility that *"data generated in service user-led interviews is to some extent qualitatively different from the university researcher-led interviews"* and that *"the same set of data is interpreted very differently by service user and conventional university researchers"* (p193). The authors caution that their study was small and their findings could reflect the fact that participants had different things to talk about in their interviews or that there were differences between individual researchers rather than the two groups (service user and professional researchers). However, they also concluded that a collaborative approach between service user researchers and

university researchers would lead to the production of more complex data and analysis that offered greater insights into their qualitative research question. Their findings support Hammell's (2001) challenge to qualitative researchers to consider "*if study participants were not involved in the research process from design to analysis, why were they not involved?*" (p232).

User involvement in interpretative phenomenological analysis

Although IPA is a relatively new qualitative research approach, some examples of user involvement in IPA research have been reported. Some researchers claim that user involvement is inherent within IPA studies because of the ideographic nature of the approach and the ability of participants to influence the data gathering process; however, a small number of studies have sought a greater involvement of users. Some practical and philosophical challenges to involving users in IPA research are discussed in this section.

In many IPA studies, participants are patients or users of health services. Some researchers argue that IPA studies make a valuable contribution to the NHS agenda of user involvement in the development and evaluation of healthcare services by prioritising the participants' voice and expanding understanding of health care and illness from the perspective of the service user or patient (Pringle et al. 2011). This is inherent within an ideographic approach in which the participant's viewpoint is centralised and given authority as that of the "experiential expert" (Smith, Flowers and Larkin 2009). Data gathering is often described as participant-led as the flexibility of the IPA approach means that the participant/user is able to bring up issues of importance to them that may not have been anticipated by the researcher. Gaining insight into the patient experience of living with a health condition supports the aims of user involvement in health research by helping services to develop treatments and interventions that address issues of concern or interest to patients, as illustrated in the studies by Jelbert et al (2010) and Murray and Harrison (2004). IPA studies focusing on patients' experience of receiving health care services also support the aim of user involvement in health research by exploring the relationship between patient's experience and the method of service delivery (Cassidy et al. 2011, Charman, Harms and Myles-Pallister 2010, Dean et al. 2005). The authors of such studies hope that the primacy of the user voice in their findings will lead to the development of services that address the health care needs of particular patient groups more effectively. While the role of the service user as a *participant* is identified and valued in these IPA studies, elsewhere users have been involved at additional stages of the research process.

One IPA study that is described as "patient initiated" explored the experience of patients requiring strong opioid drugs for chronic pain (Blake et al. 2007). This topic area was identified by a patient who was interested in finding out about the experience of patients with chronic pain and whether

they shared his concerns about the effects of long term use of medication. The patient/service user identified the area of study and also participated in a focus group that provided data for the study and led to the development of a detailed interview schedule for use with a further 10 participants.

Service users have been involved in developing an interview schedule in a number of IPA studies, including studies by Erskine (2012) who developed questions in consultation with a young man with sickle cell anaemia as well as a Consultant Paediatrician and Clinical Psychologist, and Groark et al (2011) who discussed their study with a young asylum seeker as well as professionals working in the field to “*develop the interview in a contextually relevant way*” (p425).

The study by Martindale et al (2009) is an unusual example of active collaboration between service user researchers and practitioner researchers using IPA. In this study exploring clinical psychology service users’ experiences of confidentiality and informed consent, a service user practitioner conducted a focus group with other service users to develop an interview schedule which he then used during interviews with eleven further participants. The service user researcher played a central role in data analysis in collaboration with the practitioner researcher and helped to disseminate the research findings. An earlier IPA study by Pitt et al (2007) researching recovery from psychosis, is described as a “user-led” project. Two user researchers were active agents in the research process (Smith, Flowers and Larkin 2009), carrying out all stages of the research with supervision from clinical psychologists with research experience. The area for study was identified by the user researchers who met regularly with a steering committee of other service users to make decisions about the study design and to gain their input into the analysis. The authors suggest that this role of service users in the study enhanced insight into the subjective experience of recovery and reduced the risk of personal bias from the primary investigators.

Some philosophical and methodological challenges to involving users in IPA research need consideration. One factor considered by contributors to the IPA website and discussion forum (which can be accessed at <http://www.psych.bbk.ac.uk/ipa>) is the critical and interpretive role of the researcher in the analytical process. Smith et al (2009) describe IPA as involving a double hermeneutic in which the researcher attempts to make sense of the participants’ attempts to make sense of their own experience. The dual role of the researcher is described as being “*both like and unlike the participant*” (p35). The researcher is *like* the participant in that they are human beings who draw on their everyday experiences to make sense of the world, but *unlike* the participant in that the researcher only has access to the participant’s experience through what he or she reports about it, and sees this experience through their own, experientially influenced lens. It could be argued that service user researchers are *too like* the participants or too close to their worlds to

separate their experiences, a criticism acknowledged by Blake et al (2007). User-researchers might be too quick to make interpretive leaps based on their own experience which could distract them from focusing on the experience of the participant. This, it could be suggested, might affect the credibility and validity of the findings. Yet one of Yardley's (2000) criteria for assessing the quality of qualitative research is sensitivity to context to which user-researchers have ready access. Also, unlike positivistic approaches, qualitative research does not assume to discover a generalizable truth. Indeed, an interpretative analysis which is methodologically sound and in which the perspectives of those involved in the analysis are openly acknowledged offers a potentially different and useful but no less valid insight into the phenomenon under investigation.

Smith et al (2009) state that *"prior experience of a phenomenon should not be seen as either a requirement or a barrier to exploration and understanding"* in IPA research (p162). They propose that the insider's status of user-led research provides *"a further point of comparison in the hermeneutic cycle"* (p162) and that user-led research has *"the potential to offer powerful insights"* that might not otherwise be captured. Pitt et al (2007) argued that the user researcher's personal experience of recovery from psychosis provided closer access to an *"insider's perspective"* (Smith and Osborn 2008) and was helpful in making sense of the participants' experiences. The authors also suggested that the involvement of a steering committee of service users helped to counter personal bias from the user researchers by providing a broader user perspective.

Martindale et al (2009) used the insider's perspective to deepen the level of interpretation in their IPA study by developing a research process that involved active collaboration between a user researcher and practitioner researcher. The challenges of integrating the interpretive perspectives of a user researcher and practitioner researcher were examined from both a practical and a philosophical perspective. Acknowledging the role of the researchers' interpretations in IPA, the service user researcher and practitioner researcher engaged in a process that sought to *"embrace potential difference in interpretation"* (p359). This involved combining interpretations when they were similar and subjecting different interpretations to further reflexive discussion. In some instances further discussion and reflection produced a shift in their relative positions, while at other times the two interpretations were captured and reflected on separately. At times, further discussion facilitated by a third author enabled consensus to be reached as to how the themes should be presented. A strength of this study is its attention to the role of all researchers in the interpretive process. It is reported that all researchers strived to avoid privileging one person's analysis by being self-aware and reflexive throughout the process. The authors reflected that

“Through enacting a joint analysis of data we endeavoured to increase the richness of the analytic process and consider how the differing experience of the researchers brought about a more diverse appreciation of the participants’ accounts” (p359).

This positive collaborative relationship facilitated discussion and reflection, resulting in a far richer level of interpretation. The process also meant the world views of those involved in the interpretation of data was acknowledged, used and reflected upon, thus enhancing reflexivity and ensuring that the user voice was not lost.

Rationale for involving a Research Reference Group in this study

The previous section described the policy and context for involving users in research. Justification for involving members of the public in research was offered and some challenges associated with user involvement were explored. Various models for user involvement in research were presented. The section concluded with an examination of user involvement in occupational therapy research and in qualitative studies, with particular reference to interpretative phenomenological analysis. In the following section, I explain what is meant by a ‘Research Reference Group’ before presenting the moral, ethical, political and academic reasons for involving a Reference Group in this study. There follows a description of the role of the Reference Group, their impact on the research design, data collection and analysis, and their involvement in the dissemination of initial study findings.

The Research Reference Group was established after ethical approval for the study had been granted, and included older teenagers and young adults with dyspraxia. It was not possible for the group to control all aspects of the research however, as academic protocols required that I should be the primary researcher. The study was not therefore ‘user led’ as I do not have dyspraxia myself. Involving a Reference Group in the study did, however, bring an insiders’ perspective to the research process. The following section justifies involvement of the Reference Group in the study.

Moral and ethical motivation

As a qualitative researcher and as an occupational therapist who believes in client-centred practice, the moral and ethical imperative for involving people who might be considered the ‘subjects’ of research in research that is ‘about’ them was strong. I regarded this research as not just an academic exercise but as something that I hoped would make a difference to young people by increasing understanding of DCD/dyspraxia in adolescence and helping professionals to develop interventions to support teenagers in the areas that matter to them most. Involving a Reference Group in the research design, delivery, and dissemination would ensure that the project was meaningful and relevant to teenagers living with DCD/dyspraxia and therefore a respectful and ethical use of participants’ time.

Working in partnership

Involving the Reference Group enabled me to work in partnership and support advocacy for people with DCD/dyspraxia. DCD/dyspraxia is a relatively new diagnosis and has only recently been recognised as a life-long condition (Movement Matters UK 2013). An increasing number of teenagers and adults are being diagnosed with DCD/dyspraxia and are advocating for better recognition and services for people with DCD/dyspraxia across the life span. I wanted to ensure that people with DCD/dyspraxia felt some 'ownership' of the research and that it wasn't just being driven by a personal or professional agenda. I also believed that collaboration between myself as a professional researcher and the Reference Group would lead to findings that were more insightful and would therefore have a greater impact on teenagers with DCD/dyspraxia.

Managing the balance of power

Involving a Reference Group in the research was also intended to help address concerns regarding the balance of power between myself, as an adult and professional researcher, and the teenage participants. Traditionally young peoples' perspectives in research have been "*filtered through interpretations offered by adult researchers*" (Coad 2012). I acknowledge that whilst I meet teenagers with DCD/dyspraxia as an occupational therapist and as a Trustee of the Dyspraxia Foundation, whilst I am the mother of two teenagers and while of course I was once a teenager myself, I have not experienced being a teenager with DCD/dyspraxia. Establishing a Research Reference Group of 'experts through experience' who have DCD/dyspraxia and who were close in age to the participants therefore introduced a 'dyspraxic' filter to the project and formed part of the project plan from an early stage.

Political motivation

There was a political motivation for involving a Research Reference Group in this study. This was initially less important than moral and ethical factors however, as user involvement was not a requirement of the University Ethics Committee and there was no accountability to external funders who might have required it. I did feel however that involving the Reference Group would help improve the credibility of the research, and, indeed user involvement in this project has drawn particular attention from my NHS employers. Meeting the political agenda of 'patient and public engagement' through the involvement of the Research Reference Group therefore helped to raise the profile of the study and awareness of the needs of teenagers with DCD/dyspraxia in an organisation that previously had limited knowledge in this area.

Academic motivation

The academic motivation for involving the Reference Group in this project was partly driven by the requirement to make original contributions to knowledge. As demonstrated previously, knowledge

about DCD/dyspraxia in adolescence is limited and collaboration between professional researchers and service users in DCD/dyspraxia research is rare; therefore the involvement of the Reference Group is offered as a novel methodological approach which helps to meet academic requirements. In addition, scientific journals and conference committees increasingly recognise the value and importance of user involvement and have an expectation that researchers will demonstrate how members of the public or patients have been involved in a study. The involvement of the Reference Group would I hoped, raise the status of this research and increase the potential for sharing research findings at conferences and in peer-reviewed publications.

Role of the Research Reference Group

Having described the moral, ethical, political and academic motivation for user involvement in this study, I will now describe *how* the Reference Group was involved in the research. Their role was to:

- ensure that the project design was appropriate and relevant to teenagers with DCD/dyspraxia;
- identify issues that might be of interest or concern to teenagers with DCD/dyspraxia for inclusion in the interview schedule ;
- add an insiders' perspective to the analysis; and
- help share the research findings.

How older teenagers/young adults with DCD/dyspraxia were recruited and involved in the Reference Group is described below. Their involvement was guided by the principles of good practice for user involvement in research developed by Wright et al (2010).

Recruitment and membership of the Research Reference Group

Members of the Reference Group were recruited through advertisements placed on the Dyspraxia Foundation website in October 2009 (Appendix D). A total of 19 people aged from 16-31 years enquired about the project and were sent a Reference Group Information Sheet, a contact information sheet (which included some demographic information) and a consent form. The age range was chosen to be close to that of the project participants but broad enough to ensure an adequate number of people were recruited. 8 individuals attended at least one of the six Reference Group meetings. Pseudonyms are used to preserve the confidentiality of group members. Details of group members are included in Table 7.

Table 7: Membership of the Research Reference Group

Pseudonym	Gender	Age at first meeting	No. meetings attended
Andrew	M	31	2
Bryn	M	17	6
Collin	M	20	2
Dawn	F	24	2
Ellie	F	17	3
Felicity	F	16	2
Gavin	M	21	1
Imogen	F	17	2

The group involved equal numbers of males and females with males attending a total of 11 sessions and females 10. The number of females volunteering to be part of the Reference Group was interesting as DCD/dyspraxia is more frequently diagnosed in boys than girls (Lingam et al. 2009). However, the gender balance is similar to that of participants in adult studies reported and discussed in Chapter 2 and perhaps reflects a more equal gender prevalence of DCD/dyspraxia than many clinical studies imply. All group members reported that they had been diagnosed with dyspraxia (or in one case “childhood clumsiness”) either as a child or in adulthood, with one person reporting an additional diagnosis of Asperger’s Syndrome. All group members referred to themselves as having ‘dyspraxia’; none used the term DCD.

Potential group members were sent information about the date, time and location of Reference Group meetings by email, sent from an email account set up specifically for this purpose (teenresearch@dyspraxiafoundation.org.uk). The postal address of the Dyspraxia Foundation was used for communications sent by post (for example the return of signed consent forms and contact information sheets prior to the first meeting) to avoid sharing my personal contact details. Group members were however provided with my mobile phone number in case they needed to get in touch urgently.

What the group did

Six Reference Group meetings were held over the course of the project. Meetings were held on a Saturday in a meeting room in the West Midlands which was easy for group members to reach by car or public transport. Reasonable travel costs were met by the researcher and refreshments were provided. Meetings lasted up to two hours and were chaired by me. An example of a Reference Group meeting plan/agenda is included in Appendix D.

Table 8: Reference Group meeting dates and purpose

Date of meeting	Primary purpose of meeting
January 2010	To identify topics for inclusion in interview schedule (participants aged 13).
June 2010	Analysis of first round of interviews
November 2010	To identify topics for inclusion in interview schedule (participants aged 14)
May 2011	Analysis of second round of interviews
November 2011	To identify topics for inclusion in interview schedule (participants aged 15 years)
September 2012	Analysis of third round of interviews and review of the experience of being a member of the reference group

Reference Group involvement in project design

Due to university procedures, it was not possible to approach potential Reference Group members until after the research proposal had been written and ethical approval granted. By the time of the first Reference Group meeting in January 2010 therefore, the research approach was already established as IPA with individual interviews as the method of data collection. The extent of the user involvement in research was therefore limited by the academic and ethical approval process.

Some group members were interested in the research design. While Andrew thought it would be useful to gather more quantitative data, the value of doing this with a sample size of not more than 10 was questioned by others. The group agreed that it would be useful to gather qualitative information about the experience of being a teenager with DCD/dyspraxia and made suggestions about how this could be achieved. Bryn was keen that participants should have the opportunity to raise issues, even if they hadn't been thought of by the researcher or Reference Group, confirming the appropriateness of semi-structured interviews as the data gathering method:

Bryn: Do you think you could have some kind of, I'm not really sure what the psychological term for it is, but some questions that don't aim to give you direct answers?

Researcher: Open questions?

Bryn: Not as much open questions which allow them to say what they want to say, which is useful, or questions which allow them to say what you want them to say, like at school what help they think they need because I mean, we often know. I mean questions that aim to find out completely different things.

Reference Group involvement in data collection

The role of the Reference Group in data collection was to identify topic areas that might be of interest or concern to teenagers with DCD/dyspraxia at age 13, 14 or 15 years (depending on the

stage of the study) to be included in the interview schedule. Each year I asked the group what they were doing at that age; what was going on for them at school; what clubs or organisations they belonged to and whether there was anything they particularly remembered from that time. From the resulting discussions I reflected back to the group questions that might encourage participants to share their experience of similar issues.

After each meeting I drafted an interview schedule based on questions raised by Reference Group members. Disappointingly, although I circulated draft interview schedules to Reference Group members by email I received very little feedback. Setting up a closed group using social media might have increased members' engagement by creating an environment that invited discussion, rather than asking for formal feedback. The richness of the data gathered during the interviews and discussion of themes by the Reference Group afterwards indicates however, that the interview questions were appropriate and relevant.

Reference Group involvement in data analysis

Involving the Reference Group in the data analysis recognised that older teenagers/young adults with DCD/dyspraxia could offer additional and potentially deeper insights into the lives and experiences of the participants than I would uncover myself as a "non-dyspraxic" researcher. At a Reference Group meeting after each round of interviews I selected a number of quotes from the interview transcripts and presented these to the group for discussion. Using their personal experience, Reference Group members discussed what they thought participants meant by what they had said. I added my perceptions to the discussion so that together we developed a shared understanding of the meaning behind participants' words. The process was iterative in that one discussion informed the next; we also moved from discussion of individual quotes to groups of related quotes, reflecting the shift from individual to group analysis that is typical in IPA research (Smith, Flowers and Larkin 2009).

It could be argued that Reference Group input into the analytical process was limited by having access only to quotes selected by me rather than to complete interview transcripts. The decision to present only quotes to the group for discussion was made for pragmatic reasons as interview transcripts were up to 30 pages long. Other researchers have helped user researchers manage large amounts of interview data by presenting vignettes for discussion (Tuffrey-Wijne and Butler 2010). I was reassured by comments made by Reference Group members that the quotes I had selected were relevant and meaningful to them:

Bryn: I think from what you've picked out (participant quotes) you are really getting a feel for how this is, cos you've picked out the things which we've said "yes" to. That's not us saying yes to the things you're picking out, that's you picking out the right things.

Dawn: Yeah. There wasn't any moment when we all went "um, don't know about that, that's not affecting me"

Ellie: Every problem has affected at least one of us.

Ideally, there would be greater active collaboration between members of the Reference Group and myself as researcher in the analytical process. Additional meetings to discuss emergent themes would have enabled us to further develop and integrate our respective interpretative perspectives (Martindale, Chambers and Thompson 2009). However, resources and project timescales did not allow for this. Despite these limitations our respective interpretative positions made us sensitive to different aspects of the data and led to deeper understandings than I would have been able to access on my own.

Reference Group involvement in dissemination

Members of the Reference Group were motivated to disseminate the research findings and have helped to write articles and co-present at conferences and events: copies of conference abstracts, articles and academic posters are included in Appendices G-I. As suggested by Staley and Minogue (2006) user involvement in dissemination activities helped to raise the academic and professional profile of the study as evidenced by reference to one of our papers in the College of Occupational Therapists Research and Development Bulletin, November 2013 (Appendix J). Reference Group members were also committed to ensuring that the findings were shared with a non-academic audience by presenting at Dyspraxia Foundation events and writing articles for the newsletter. The Dyspraxia Foundation website also includes a link to a film commissioned for our workshop at the INVOLVE conference 2012. The film http://www.youtube.com/watch?v=aJsW8NtUI_g, explains why the Reference Group was involved in the research and what members gained from the experience. Further reflections on the benefits for members of involvement in the Research Reference Group are included in Chapter 8.

Chapter Conclusion

This chapter presented the context for user involvement in this study and explored the benefits and challenges of involving service users in research. Information about the involvement of members of the public in occupational therapy research and in qualitative research, particularly IPA was offered. My rationale for involving a Reference Group in this study was presented and I described the group

membership, their role and involvement in the study design, data collection, data analysis and dissemination of findings. Later in Chapter 8 I examine the challenges and impact of user involvement in this study.

This chapter acknowledges and foregrounds involvement of the Reference Group in the study. Later in Chapter 8 I reflect on my own influence on the study. Being open about the influence of me and the Reference Group on the study process, analysis and findings, allows the reader to interpret the study findings/conclusions in relation to their own knowledge standpoint and context. In the following chapter I describe the research process and method chosen to answer the research question “How is life experienced by adolescents with DCD/dyspraxia from their own perspective?”

Chapter 4

Methodology

Chapter 4: Methodology

Chapter 2 presented a review of the literature, identifying a deficit in knowledge and outlining the need for further insight into the experience of teenagers living with DCD/dyspraxia from their own contemporaneous perspective. This chapter justifies the selection of interpretative phenomenological analysis (IPA) and examines its use in occupational therapy research. The second part of this chapter provides a detailed description of the research design, including the recruitment of participants, data collection procedures and the analytical process. A summary of the reflexive approach and strategies for ensuring the credibility and trustworthiness of the findings are also presented.

Methodological paradigm

All research methods reflect a particular philosophical approach to reality; these different epistemological perspectives also determine the way in which knowledge about the world can be legitimately gained. In this section, I examine my assumptions and understanding of knowledge and its influence on the research approach selected. I begin by considering two broad philosophical paradigms, or belief systems of world view, that inform or guide the researcher and research process (Guba and Lincoln 1994): positivism and post-positivism.

A central assumption of positivism is that there is a single, objective reality that can be measured and tested (Sim and Wright 2000). Positivist research seeks to define an objective reality through the rigorous application of scientific methods, emphasising induction, verification and the establishment of laws and relationships, and rejecting speculative and subjective evidence (Crossan 2003). Positivistic approaches to health and social research have however been criticised for ignoring the importance of the subjective experience on human behaviour (Rubin and Rubin 2005). Critics argue that it can provide only a very superficial view of the phenomenon under investigation (Crossan 2003), creating a picture of people who don't actually exist. As demonstrated in Chapter 2, DCD/dyspraxia research is dominated by positivist approaches.

By contrast, post-positivism challenges the view that there can be only one objective, observable truth (Ryan 2006); instead the subjective experience of how the world is perceived is emphasised. Reality is viewed as socially constructed and contextually bound, being the result of interaction between an individual's objective and subjective experience (Wilding and Whiteford 2005). Post-positivism has been criticised for its subjectivity, in particular the closeness of the researcher to the researched, and for its lack of reproducibility (Crossan 2003). Post-positivist researchers do not however, claim that their interpretations are definitive and can be generalised, instead asserting that their methods offer plausible truths that open up debate about the possible interpretations of

experience. I contend that the objective reality of DCD/dyspraxia in adolescence that is determined by positivistic investigation represents only one aspect of the reality experienced by teenagers living with the condition and that post-positivistic approaches have an important contribution to make to knowledge about how DCD/dyspraxia is experienced. As the aim of this study was to gain insight into the lived experience of teenagers with DCD/dyspraxia from their own perspective, a post-positivistic approach, rather than an objective investigation was required.

The research question and my epistemological position indicated the appropriateness of a qualitative research approach to enable understanding of the contexts in which teenagers with DCD/dyspraxia act and interact, and to examine the meanings that individuals attached to experiences (Sim and Wright 2000). Qualitative approaches are consistent with the post-positivist paradigm and are particularly useful when "*exploring, describing and interpreting the personal and social experiences of participants*" (Smith 2008) and for exploring complex and sensitive issues such as those that might be raised by the adolescents in this study.

Several qualitative approaches were considered for this study given their shared aim of understanding participants' experience. In his book "Qualitative Inquiry and Research Design: Choosing among the Five traditions" Crewsell (Creswell 2013) compares five qualitative approaches that offer different perspectives on a scenario or problem. As Creswell demonstrates, the choice of approach is determined primarily by the study focus, although pragmatics such as resources and time are also important. I considered adopting an ethnographic approach for this study.

Ethnographic studies focus on describing and interpreting a cultural and social group (Creswell 2013) and participants tend to be located in the same team, community or organisation (Reeves, Ayelet and Hodges 2008). Immersing myself in the world of adolescents with DCD/dyspraxia through participant observation and interviews with key individuals would have allowed me to examine their culture, social interactions, behaviours and perceptions. However I did not have ready access to a 'group' of teenagers with DCD/dyspraxia as my participants were geographically spread, while securing informed consent not only from participants but also from institutional gatekeepers (school management teams and teachers) was unrealistic within the context of this study. Furthermore, the time required for data collection in ethnographic studies is extensive and beyond that which I could reasonably commit.

Narrative analysis (Reissman 1993) was another research approach that I considered. Narrative analysis focuses on the way in which individuals create and use stories to make sense of the world. Narrative accounts are typically gathered through semi-structured interview (although material such as letters and journals may also be used) and are particularly useful when examining a life-changing

event. Analysis of language provides insights into the person's understanding of the meaning of occurrences and situations, and the integration of time and context in the construction of meaning is particularly emphasised (Riley and Hawe 2005). Narrative analysis is useful when examining a particular event, situation or activity (for example a therapy intervention). The aim of my study, to understand the lived experience of teenagers with DCD/dyspraxia in general was however broader. Also, the emphasis on language, the construction of sentences and the meanings these convey was unfamiliar to me and the time needed to understand the complexity of narrative analysis was a disincentive to use this approach.

The focus of another qualitative approach, phenomenology is to describe the meaning of the lived experience about a concept or phenomenon (Creswell 2013). Data is gathered from participants who have experienced the phenomenon under investigation, but who do not necessarily know each other (like the participants in my study). I am familiar with phenomenology and felt this approach would lead to a greater understanding of the phenomenon under investigation, i.e. the lived experience of teenagers with DCD/dyspraxia. In the following section I examine phenomenology and hermeneutic phenomenology in order to make transparent the decision to adopt IPA for this study. In doing so I make clear my researcher stance and how the phenomenological paradigm shaped the research process as a whole.

Phenomenology and IPA

Phenomenological research developed from the work of Husserl in the early 20th century (Smith, Flowers and Larkin 2009, Willig 2001), evolving as a way of seeking to *"understand, describe and interpret human behaviour from the perspective of the person being studied"* (Finlay 1999). It involves the careful examination of human experience by stepping aside from everyday experience and reflecting on our 'taken for granted' experience of it. A key concept in phenomenology is the notion of 'bracketing' the taken-for-granted world in order to focus on our perception of that world. Husserl argued that working through a series of 'reductions' allows the inquirer/researcher to understand the essence of a given phenomenon (Husserl 2008). IPA takes from phenomenology its concern to seek an insider's perspective on people's lived experience (Fade 2004), but differs from Husserl's phenomenology in that it accepts the impossibility of gaining direct access to the participant's life world because of the researcher's role in examining it (Willig 2001). IPA therefore extends beyond Husserl's transcendental, descriptive phenomenology by acknowledging the central role of the analyst in interpreting the personal experience of research participants (Pringle et al. 2011).

Husserl's ideas were advanced by Heidegger (Heidegger 1962) and others who developed the concept of interpretative or hermeneutic phenomenology, considering a person as someone who is involved in (or 'thrown into') a world of objects, relationships, culture and language, and viewed being-in-the world in terms of a person's perception of and relationship to those things (a concept which Heidegger refers to as 'Dasein') (Wilding and Whiteford 2005). IPA takes from hermeneutic phenomenology its acknowledgement that understanding or explaining the nature of the phenomenon is dependent on the intellectual interpretation of the subject matter made by the researcher (Larkin, Watts and Clifton 2006). The researcher is not required to set aside (or bracket) his or her own values and beliefs, but instead views these as necessary to interpret (or make sense of) the person's experience (Clarke 2009). In both hermeneutic phenomenology and IPA it is acknowledged that the researcher brings with them 'fore-conceptions', i.e. prior experiences, assumptions and ideas that will inevitably influence their interpretation of a person's experiences. However, while Heidegger argued that these fore-conceptions present an obstacle to phenomenological interpretation and should therefore be managed in a scientific way to prevent this, Smith et al (2009) contend that it may not be possible for a researcher to know what his/her preconceptions are until he or she has begun the process of engaging with the text. Furthermore Smith argues that it is possible to hold a number of conceptions of a phenomenon and to compare, contrast and modify these as part of the on-going sense-making process (Smith, Flowers and Larkin 2009).

The hermeneutic phenomenology of Heidegger (1962) and others (Gadamer 2004, Schleiermacher 1998) evolved from the study of historical documents and texts and the desire to understand not just the exact and objective meaning of the text, but also the writer and the meanings or intentions that are hidden within the text (Smith, Flowers and Larkin 2009). IPA extends beyond hermeneutic phenomenology however in that it takes a more critical and speculative interpretative approach to analysis (Smith 2004). Smith (2004) argues that systematic, detailed analysis, the connections that emerge from exposure to larger bodies of data and the dialogue that the interpreter has with psychological theory mean that interpretive analysts offer a perspective on the text that that author cannot. As a consequence interpretative researchers "*might offer meaningful insights which exceed and subsume the explicit claims of our participants*" (Smith, Flowers and Larkin 2009). The dynamic hermeneutic process of examining individual parts of a text to understand the whole, and looking to the whole to understand individual parts aligns with the iterative 'method' of analysis for IPA researchers. A description of the process of analysis undertaken in this study, illustrating the hermeneutic cycle as an iterative process, is described later in this section.

A particular feature of IPA is that of the 'double hermeneutic'; that is, the researcher attempting to make sense of the participant who is trying to make sense of their own experience. Smith et al (2009) suggest that IPA combines both a 'empathic' hermeneutic – trying to adopt an 'insider's' (emic) perspective to see what the experience is like from the participant's point of view – with a 'questioning' (etic) hermeneutic – looking at the participant's experience from a different angle, asking questions and puzzling over the experience through the researcher's own, experientially-informed lens. In this way, IPA moves away from what the participant would say about their experience, towards an interpretative account as made by the researcher. IPA goes beyond Heidegger's hermeneutic phenomenology however, allowing the researcher to produce a theoretical framework which is based on, but which may exceed or transcend the participants' own words and conceptualizations of the phenomenon in question (Larkin, Watts and Clifton 2006).

Another major influence on the development of IPA marking it out as different from some other qualitative approaches is ideography. In contrast to positivist approaches which are concerned with making claims at a population level or with establishing general laws of human behaviour, ideography involves systematic, deep analysis at an individual level (Smith and Eatough 2006). The aim is to understand how particular things (events, processes, relationships for example) are understood from the perspective of particular people in a particular context (Smith, Flowers and Larkin 2009). This study is ideographic in its commitment to analysing a small number of individual cases in great detail before searching for patterns and themes across the group as a whole, whilst at the same time preserving divergence of experience within the sample. More detail about the process of analysis, moving from the development of individual to shared themes is described later in this chapter.

IPA was chosen for this study because of its focus on developing a deep understanding of how individuals experience and interpret events for themselves (Huws and Jones 2013). The aim was not to simply describe the experience of teenagers living with DCD/dyspraxia as a phenomenon, but to develop an understanding of the subtlety and complexity of teenagers' own interpretation of their lived experience. In contrast to phenomenology therefore, the role of the researcher (and in this case also the Reference Group) in the process of analysis is acknowledged and foregrounded. The interpretive aspect of IPA was a particular factor influencing my choice of this approach for this study. Rather than set aside my experience as an occupational therapist, mother of two teenagers and volunteer with the Dyspraxia Foundation, my experience offers unique opportunities to develop an understanding of the lived experience of DCD/dyspraxia during adolescence. Whilst my interpretations, which are also informed by the insights offered by the Reference Group might be

different to those of another researcher, they are no less valid and represent one version of reality that might be useful to other occupational therapists and people working with teenagers who have DCD/dyspraxia. The interpretative element of IPA therefore offered an opportunity to use my personal and professional experience to move beyond participants' words to develop a conceptualization of the lived experience of teenagers with DCD/dyspraxia as presented in Chapter 7.

IPA and occupational therapy

The previous section provided a rationale for the use of interpretative phenomenological analysis; here the relevance of IPA for occupational therapy researchers is explored. Much early IPA work was in the field of health psychology although the approach is now used widely in other areas of psychology such as counselling, social and educational psychology (Smith 2004). More recently other health related disciplines including dietetics (Fadé 2004), nursing (Pringle et al. 2011), physiotherapy (Cassidy et al. 2011, Dean et al. 2005) and occupational therapy have adopted IPA as a relevant approach in their field.

Strong arguments have been made for the use of phenomenological research methods in occupational therapy (Finlay 1999). Wilding and Whiteford (2005) suggest that the phenomenological approach has become favoured because it *“allows for the illumination of meaning ascriptions in context and, as such, may be seen to exemplify occupational therapy’s concern with environment and holism”* (p99). A key element of phenomenological research is that participants are considered experts in their own experience and that by telling their own stories in their own words they offer researchers an understanding of their thoughts, commitments and feelings (Reid, Flowers and Larkin 2005). The focus on exploring ‘lived experience’ through phenomenological research aligns closely with client-centred occupational therapy which is concerned with examining an individual’s experience in the context of their unique environment and the activities or roles that make up their everyday life (Hammell 2001).

Both client-centred practice and qualitative research involve a collaborative dialogue between the therapist or researcher and the client/carer or participant who together construct an understanding of the situation or the phenomena in question. The researcher’s role is implicit in the analytical research process. In clinical practice, occupational therapists listen to their client’s personal story and apply theory and knowledge to interpret their client’s personal perceptions and experiences (Sumsion 2000). Like the IPA researcher, the occupational therapist attempts to capture both what is said and what is meant (Cronin-Davis, Butler and Mayers 2009) in order to develop appropriate interventions to meet the client’s needs. In this way the occupational therapists’ beliefs and prior

understanding (like those of the IPA researcher) are necessary for making sense of others' experiences (Hawtin and Sullivan 2001). Cronin Davis et al (2009) conclude that IPA is a suitable research approach for occupational therapists as it enables participants to tell their own stories whilst allowing for professional interpretation, likening this to the narrative reasoning process that is embedded within occupational therapy practice.

Part of the IPA process involves a higher order interpretation through which connections are made and which contribute to the development of theory. Clarke (2009) advocates IPA as a research approach that not only demonstrates the complexity of occupational therapy but which can also make connections that promote understanding of the intrinsic relationship between occupation, health and well-being. Pettican and Prior's study of the transition from work to retirement (Pettican and Prior 2011) and the study by Reynolds and Prior (Reynolds 2003) of the meanings of artistic occupation for women living with chronic illness are examples of how IPA has been used to develop such an understanding from an occupational therapy perspective. Cronin-Davis et al (2009) and Clarke (2009) argue that IPA is consistent with the values and principles of occupational therapy and its use will help to develop a robust research-driven evidence base for occupational therapy that supports the value of the profession and provides a solid foundation for practice.

The findings from IPA research have been used to develop interventions and services that more effectively meet the needs of clients, carers and staff members. Reid et al (2005) promote IPA as a useful way of examining clients' priorities which can help to explain why people who use health services may not take the professional advice offered, as illustrated by Dean et al (2005) who examined patients' and physiotherapists' perceptions of adherence to therapeutic exercise for low back pain, identifying several factors that might hinder the adherence process, in particular the pressure on time as perceived by therapists and patients. Another IPA study explored ways in which participants with rheumatic conditions had successfully incorporated mindfulness practices into their everyday lives (Hawtin and Sullivan 2001). Clarke (2009) argued that the use of IPA research to reflect on the experiences of clients, carers and occupational therapists could lead to changes that would enhance occupational therapy service provision.

Research Design

The first part of this chapter provided a rationale for the methodological paradigm, research strategy and approach taken to explore the lived experience of teenagers with DCD/dyspraxia. I also examined the synergy between IPA and occupational therapy client-centred practice. In this next section, I demonstrate how IPA was employed to develop an understanding of the complexities of the experience of living with DCD/dyspraxia as a teenager, by setting out the research design, including a detailed description of the process of analysis and the shift from analysis of individual transcripts to a position of analytical interpretation.

Ethical approval

Ethical approval for this study was awarded according to University procedures in July 2009.

Sampling

Qualitative studies seek to provide a depth of knowledge about a phenomenon and the natural context in which the phenomenon is experienced. Unlike quantitative studies there is no aim to collect data from a large number of subjects in order to claim that the findings are representative of a population and can be generalised. Instead qualitative research "*seeks to produce in-depth analyses of a small group's accounts rather than representative samples*" (Brocki and Wearden 2006). Indeed, Reid, Flowers and Larkin (2005) suggest that IPA challenges "*the traditional linear relationship between "number of participants" and the value of research*" (p22). The aim of the sampling process was therefore to identify a small group of people for whom the research question was relevant, in order to carry out a very detailed interpretative analysis of their accounts.

IPA study samples are necessarily small because of the ideographic method of enquiry, i.e. the highly detailed and intensive analysis of individual accounts. The emphasis is on gathering quality information that will lead to a deeper understanding of a participant's experience (Clarke 2009). Smith and Eatough (2006) built a case for a sample size of one, arguing that a great deal can be learned from an in-depth analysis of one person's experience of a phenomenon and that much can be learned by exploring the connections between different aspects of the person's account. Reid, Flowers and Larkin (2005) report however, that more typically studies have an average of 15 participants. They advocate for a maximum of 10 as the process of in-depth analysis is a very time intensive process and it would be difficult to do justice to each participant's account if sample sizes were large and the project was not supported by a team of researchers and funding. Indeed, Collins and Nicolson (2002) argue that analysis of large data sets may result in the loss of "*potentially subtle inflection of meaning*" (p626). Brocki and Wearden (2006) counter criticism that a small sample

limits the value of IPA research by suggesting that, given adequate contextualization of the data, small samples can provide an extremely useful perspective on the phenomenon under investigation.

Smith and Eatough (2006) note that there are typically 6-8 participants in postgraduate IPA studies in the fields of clinical and health psychology. They argue that this sample size provides enough cases to allow for the examination of similarities and differences between participants but not so many that the researcher is overwhelmed by the data. However, they caution against the reification of a certain figure as the size of the sample will depend on a number of factors. These include:

- the researcher's commitment to the case study (individual) level of analysis;
- the richness of data offered by individual cases;
- how the researcher wishes to compare and contrast cases; and
- pragmatic limitations such as time and resources.

Other qualitative methods apply the concept of 'data saturation' i.e. when no new themes emerge from the data analysis, to identify the point at which sufficient participants have been recruited.

Data saturation does not sit comfortably within IPA research because the cyclical, iterative nature of data analysis (the process of analysing and reanalysing passages in the light of insights gained from other sources) means that new analysis could go on ad infinitum. Sample size is more likely to be limited for practical reasons such as time and the willingness of potential participants to volunteer for a study.

Sampling in IPA is purposive in order to recruit a clearly defined group of participants for whom the research question has relevance and personal significance. In contrast to nomothetic research, participants are not selected because they are representative of a population but because they represent a perspective on the phenomena in question (Brocki and Wearden 2006). Typical methods for purposive recruiting of participants include referral from gatekeepers, through the researchers' own contacts, or by snowballing (i.e. by participants making contact with other potential participants) (Smith, Flowers and Larkin 2009).

Participants in IPA research are sampled to form a homogeneous group so that they can offer insights about the phenomenon from a position of shared experience. Making the participants as similar as possible means the researcher can examine variability within the group in detail, analysing both convergence and divergence of experience and meaning for individuals (Brocki and Wearden 2006, Smith 2004). The homogeneity of the sample may however, be affected by practical issues such as how easy it is to find people who have shared the same experience, or by questions of interpretation such as the variability of people's experience and whether this can be captured within the scope of the project. Clarke (2009) suggests occupational therapy clients as possible examples of

people who have a particular shared experience, for example living with a specific condition or experiencing a particular intervention. In some cases the sample may be divided up to explore the phenomenon from different perspectives, for example the experience of physiotherapists and patients about adherence to therapeutic exercise for low back pain (Dean et al. 2005).

Sampling for this study was guided by the commitment in IPA studies to providing a very detailed interpretative account of the experiences of individuals for whom the research question had meaning and relevance (teenagers living with DCD/dyspraxia); and by practical constraints such as time and resources. A sample size of not more than 10 participants for each round of interviews was therefore chosen as an appropriate figure. Sixteen interviews were completed in total.

Identifying potential participants

For the purposes of this study, I needed to identify individuals who had experienced the phenomenon (being a teenager with DCD/dyspraxia), who had the knowledge and ability to articulate their responses (Sim and Wright 2000) and who were prepared to participate in the study. The following inclusion criteria were established:

- 13 years old in January 2010; 14 years old in January 2011 and 15 years old in January 2012;
- Diagnosed with DCD or dyspraxia by a doctor/ paediatrician;
- Willing to participate in the study and share their experiences;
- Ability to provide written consent to participate;
- Written consent provided by a parent/legal guardian.

These ages were chosen as times when young people are experiencing many of the biological, social and psychological challenges typically associated with adolescence but are not usually involved in public examinations or moving to a new school. The focus of this study is on the general experience of being a teenager with DCD/dyspraxia, rather than their specific experiences of diagnosis, exams or school transition.

Participants were required to have a primary diagnosis of dyspraxia or DCD. This diagnosis should have been made (or confirmed) by a medical doctor or paediatrician in order that other conditions that may present in a similar way but which follow a different developmental course (for instance cerebral palsy or neurofibromatosis) had been excluded (American Psychiatric Association 2013). Participants with additional diagnoses of, for example, dyslexia, attention deficit disorder, speech/language impairment or Asperger's Syndrome were not excluded as co-occurrence of other developmental disabilities is typical in people with DCD/dyspraxia (Kaplan et al. 1998). As the purpose of this study was to explore the reality of living with DCD/dyspraxia it was important that

issues arising as a result of these overlapping conditions were not ignored. However, it was a requirement that these diagnoses were secondary to dyspraxia or DCD as the phenomena under investigation was the experience of living with DCD/dyspraxia.

Recruitment

Participants were recruited through advertisements placed on the Dyspraxia Foundation website and in the autumn edition of Dyspraxia News 2009 (Appendix E). Information about the study was also shared with occupational therapists in the West Midlands who signposted interested families to the Dyspraxia Foundation website for further information. The Dyspraxia Foundation website is freely accessible to the public and at the time of recruitment received an average of 1000 hits per day. Dyspraxia News is circulated to around 1500 members of the Dyspraxia Foundation including parents, carers and professionals.

Working with a voluntary organisation or self-help group is reported to help with the recruitment of participants by enhancing the credibility of the study and providing reassurance to people who might otherwise be suspicious about researchers' motives (INVOLVE 2012b). Voluntary agencies can help researchers by providing access to people who might otherwise be hard to reach, for example people from black and minority ethnic communities (INVOLVE 2012c). Working with the Dyspraxia Foundation helped recruitment by assuring potential participants that the project was meaningful and relevant. Dyspraxia Foundation staff were able to answer questions about the project and the project's aims and methods before putting potential participants in contact with the researcher. The Dyspraxia Foundation also promoted the project to a large number of potential participants across the UK. Teenagers with DCD/dyspraxia are a difficult group to reach as some therapy services are restricted by age (College of Occupational Therapists and National Association of Paediatric Occupational Therapists 2003). Ideally members of the Reference Group would have been involved in the recruitment of participants; however, project timescales and university procedures for securing ethical approval meant that recruitment of participants and members of the reference group occurred simultaneously.

There are some disadvantages to recruiting participants through voluntary organisations. Membership of the Dyspraxia Foundation is open to anyone including those who perceive themselves to have DCD/dyspraxia but who may not have received a formal diagnosis. It was therefore necessary to develop procedures to ensure that study participants could be appropriately included. In addition, the Dyspraxia Foundation is a national organisation with members drawn from all over the UK and it was likely that I would be required to commit time and resources to travel to carry out interviews. This proved to be the case. However, the disadvantages in terms of time and

travel were outweighed by the benefit of recruiting participants with diverse experience of and access to local services.

Table 9: Study participant details

Pseudonym	Ethnicity	Area of residence	Interviewed age 13	Interviewed age 14	Interviewed age 15
Adam	Black/Caribbean	West Midlands	Yes		
Billy	White British	Kent	Yes	Yes	Yes
Callum	White/Asian	Dorset	Yes		
David	White British	West Midlands	Yes	Yes	Yes
Eden	White British	Yorkshire	Yes		
Freya	White British	East Anglia	Yes		
George	White British	Greater London		Yes	Yes
Harry	White British	Greater London		Yes	Yes
Ian	White British	Dorset		Yes	Yes

Participants

In November/December 2009 13 families contacted me either by email, letter or by telephoning the Dyspraxia Foundation expressing interest in the study. Of these, two young people sent emails themselves while a further 8 parents specifically said that their son/daughter had asked them to make contact as they wanted to be involved. Six young people fulfilled the inclusion criteria and participated in interviews during February/March 2010. All participants were aged 13 and were either in school year 8 or year 9. This sample size is consistent with that suggested by Smith and Eatough (2006) as appropriate for a post-graduate IPA study, allowing for a detailed case by case analysis whilst providing sufficient data to produce a detailed interpretative account. A sample of six was also appropriate given the project resources and timescale for data collection and analysis.

In January 2011 I sent emails to young people who had previously participated in the study and those who had either been too late to participate in the first round of interviews or for whom a suitable date could not be arranged. The study was promoted once again on the Dyspraxia Foundation website. Interviews were arranged with 5 young people during February 2011 and included two young people who had participated in Phase 1. All participants were aged 14 at the time of the interview and were either in school year 9 or year 10. I was disappointed that only two previous participants remained involved with the project but reflected that it was perhaps unrealistic to expect young people to remain interested in the study over a prolonged period at a time when they might be facing additional challenges and demands associated with adolescence. I was both pleased and relieved to recruit three additional participants as this ensured I had sufficient data for analysis.

In January 2012 I sent emails to all individuals who had been interviewed in 2011 and was delighted that all agreed to participate again. The study was also promoted on the Dyspraxia Foundation website with a particular request for new female participants to join the study. Interviews were arranged with 5 young people during February 2012 and included two young people who had participated in both Phase 1 and Phase 2, and three participants previously interviewed in Phase 2. All participants were aged 15 at the time of the interview and were either in school year 10 or year 11. Unfortunately despite an expression of interest by one young lady she decided not to participate, explaining that she didn't want to focus on dyspraxia as she'd endured a lot of assessments in recent years. This was disappointing as I was keen to explore the perspective of another female participant. Her response did however make me think about the relationship that teenagers have with their diagnosis, an issue which emerged as a strong theme and which is explored in Chapter 6.

A summary of those who enquired but who did not participate in the study is included in Table 10.

Table 10: People who chose not to participate in the study

Sex	Reason
Female	Withdrew for personal reasons
Male	Withdrew for personal reasons
Male	Unable to arrange suitable interview date
Male	Applied after interview dates
Male	Not yet 13
Female	Not yet 13
Male	Unable to arrange suitable interview date
Female	Withdrew for personal reasons

Participant details

To provide context for the study, a brief biography of each participant based on information they offered during their interviews is provided. Pseudonyms were chosen by me and reflect the order in which interviews took place.

Adam lives with his Mum, his older brother and his Nan. He sees his Dad infrequently. Adam travels to his local mainstream secondary school by bus and has a Statement of Educational Needs. Dyspraxia was first suggested by his teachers when aged around 7 years and was confirmed more recently by a Consultant Paediatrician. Adam sustained a head injury following a road traffic accident 8 months prior to the interview after which he spent two weeks in hospital. Adam received support for his dyspraxia from an occupational therapist prior to his accident and again more recently. He enjoys occasional go-karting trips with his friends and playing computer games.

Billy lives with both parents and his twin sister. Billy attends a selective boys grammar school and travels there by bus and on foot. He was diagnosed with dyspraxia aged 8 years and has no additional diagnoses. However there is a family history of dyslexia. Billy does not have a Statement of Educational Needs but receives support from the learning support department at his school. Billy had occupational therapy and physiotherapy when younger, and when first interviewed was receiving support from his GP and a hypnotherapist for anxiety. Billy is a keen sportsman, being a member of a local rugby club. He is also a Scout and hopes to become a lawyer.

Callum lives with both parents and his younger sister. Callum attends a non-selective mainstream secondary school for boys and is driven there each day by his parents. Callum was diagnosed with dyspraxia by a consultant community paediatrician aged 11 years. He has no additional diagnoses. Callum has received help from an occupational therapist and a speech and language therapist. He does not have a Statement of Educational Needs. He is a keen musician and plays tennis as a member of a local club.

David lives with his Mum and his younger sister; a baby brother arrived when he was aged 14. David sees his Dad, who lives some distance away every couple of months. He attends a non-selective mainstream boys school which David and his Mum chose because of its provision for pupils with special needs. David takes two buses to get to school each day. He was diagnosed with Asperger's Syndrome and dyspraxia by a consultant paediatrician when aged 6 or 7 and had occupational therapy when younger. He enjoys playing football and was elected by his peers to be his Form Rep. He hopes to become a teacher in the future.

Eden lives with his Mum, his step-Dad and his younger sister. He sees his Dad every other weekend and his step-brother stays alternate weekends. Eden walks to his local mixed secondary school. He was diagnosed with attention deficit hyperactivity disorder (ADHD) and dyspraxia by a paediatrician when aged 5 or 6. There is a strong family history of dyspraxia, dyslexia and ADHD. Eden has had occupational therapy and physiotherapy in the past. He is very interested in Japanese animation and likes to read fantasy literature and play computer games. He occasionally attends a local youth club. Eden hopes to become computer games designer when older.

Freya lives with her Mum, her step-Dad and older sister. She sees her Dad occasionally. Freya attends a mixed mainstream secondary school which she travels to by bus. She was diagnosed with verbal dyspraxia by a paediatrician at around 2 years of age and received regular help from a speech and language therapist when younger. Motor dyspraxia was identified by a paediatrician when Freya was nine or ten years old. Freya receives some support for her learning at school. She has a wide circle of friends and a clear plan for a future career in hairdressing.

George lives with his Mum, Dad and younger sister. He attends his local mixed comprehensive school and travels there by bus and on foot. George was identified as having 'dyspraxic tendencies' whilst at nursery and received some therapy support at this time. His diagnosis of dyspraxia was confirmed by a paediatrician at age 10. He also has severe asthma and other related health problems. George does not have a Statement of Educational Needs. He enjoys a good mix of social and individual pastimes, and counts among his friends at home a number of people with additional needs. He hopes to work in public service when older.

Harry lives with his Mum, his step-Dad and two younger siblings. He has a Statement of Educational Needs and attends a special independent school for children with additional needs having experienced a nervous breakdown at a previous school. Harry has a number of diagnoses including Asperger's Syndrome, dyslexia and deafness for which he (sometimes) wears hearing aids. He travels to school by taxi. Harry loves his pet dog, jumping on the trampoline, scuba diving and snowboarding. He hopes to become a pilot when older.

Ian lives with his Mum, Dad and younger sister. He attends an independent school that his parents chose because his previous school did not provide the support Ian required which led to him being in constant trouble. Ian was diagnosed with dyspraxia by a paediatrician aged 11 years and has previously received advice from an occupational therapist. Ian enjoys being part of a local football club and has ambitions to try new physical activities such as sky diving and American football. He hopes to work with children and young people when older.

Data collection

The most common method of data collection in IPA research is in-depth, semi-structured interviewing (Smith and Osborn 2008) although Pringle et al (2011) proposed the use of written narrative accounts, diaries, and focus groups as alternative methods. I decided against using written accounts because poor handwriting is frequently associated with DCD/dyspraxia. Requiring participants to write down their experiences might have deterred some individuals from participating, while for others it might have limited the amount and richness of data provided. Problems with legibility might also have posed a problem for me in interpreting the text. Focus groups offer the advantage of gathering data from several participants in a short amount of time. However, some individuals may not have the chance to describe their personal experiences in detail and with the same degree of intimacy in a group compared to an individual interview. Smith (2004) also suggests that the group environment might encourage some individuals to disclose personal information that they might not reveal in an interview situation and which they later regret. Separating group patterns of disclosure and dynamics from ideographic accounts can also be challenging when analysing focus group discussions. Use of email discussions, interviews via Skype and internet forum discussions are newer methods of data collection that may be useful when carrying out research with hard to reach groups or those who are geographically spread, but there is currently little published evidence to support their use.

I chose semi-structured interviews as the method of data collection to ensure that the prime areas of interest to me and the Reference Group were covered. I anticipated that interviews would allow me and participants to "*engage in a dialogue where initial questions are modified and developed in the light of the participant's responses*" (Smith and Osborn 2008), enabling teenagers to raise issues that were of concern or interest to them that the Reference Group and I had not considered. Typically a small number of open-ended questions that are broad and exploratory in nature are used to encourage participants to talk: responding to participants and following their avenues of interest enables the interview to be co-authored and shaped predominantly by the participant in partnership with the researcher (Huws and Jones 2008) rather than being guided by the researcher's preconceptions of the phenomena under investigation. By contrast, highly-structured interviews may limit the amount of detail that people are willing or encouraged to disclose, therefore providing less information for the researcher to analyse. As an occupational therapist I routinely ask young people about how they manage the tasks and activities that occupy them. I attempt to be non-judgemental and accept that young people's views are valid and reflective of their actual experience. Whilst my clinical and research interviews both aim to identify the tasks and activities that are important to an individual, my research questioning focused more on uncovering how teenagers felt

about the experiences they described, and the meanings they ascribed to their experiences. By contrast, my clinical interviews examine the supports and barriers to my clients' occupational performance so that I can identify strategies or accommodations to support them.

Semi-structured interviews were also chosen to ensure that data collected was rich in detail and suitable for analysis. Whilst typically IPA interviews are "*led by the participant and guided by the researcher*" (Clarke 2009) Smith (2004) suggests that the researcher will have a stronger role and may need to be more interventionist when interviewing children, people with learning difficulties and those whose first language is not English. Smith recommends that "*researchers should draw on their professional experience to modify existing protocols for data collection*" when working with these populations (Smith 2004). Semi-structured interviews offered opportunities for me to probe and encourage participants to expand their ideas whereas responses might be more limited in a written or video diary. The following extract from Interview 3 illustrates how I encouraged Callum to expand his answer and provide more detail:

Extract from interview with Callum, February 2010

Researcher: Would you say you like school?

Callum : Yeah, most of the time, yeah.

Researcher: OK, most of the time. Which subjects do you like doing?

Callum : English and IT, PE

Researcher: OK, and you like PE as well (notes this down)

Callum : and the things that I struggle at, the lessons are, is er, technology, like wood technology which I cut my finger doing.

Researcher: OK, tell me about that. What happened?

Callum: Well like, I was making this thing like out of wood, it's like a mechanical toy that you had to turn around, but a wooden one. So and um, I was cutting and I was holding the thing that would support and it just started bleeding. So I find it hard to do and I'm behind a lot.

Researcher: Right, so you work more slowly than others?

Callum : Yeah, and I've never actually finished a project before

Researcher: Right, how does that make you feel?

Callum : Well (sighs) I don't really like it so I don't really want to finish it really, but a bit upset that I haven't achieved it.

Process of data collection

Following the initial contact parents were sent copies of the Parent Information Sheet and Participant Information Sheet and were asked to return signed copies of the Participant Consent Form, Parent/Carer Consent Form and Participant Contact Information Sheet to me (Appendix E). University procedures required that Information Sheets were submitted as part of the ethical approval process, so the Reference Group was not involved in their production. The impact of university procedures on user involvement in research is examined later in Chapter 8. Separate information sheets were produced for potential participants and for their parents/guardians. Each contained the same information but the language was altered for the Participant Information Sheet to make it more appropriate for younger readers. This information was reiterated and the participant invited to ask any questions about the project before each interview commenced. Interview dates were arranged by email at a time to suit the participant (either at a weekend, during half term or after school) and I telephoned two days before the interview to confirm arrangements. Each interview started with a number of factual questions as a way of introducing participants to the interview process and to put them at ease, for example *“Who else lives with you in this house?”* and *“How do you travel to school?”* Gradually the questions became more exploratory, allowing participants to discuss issues of relevance and concern to themselves, for example *“Can you tell me what makes a good day for you at school?”* and *“Tell me about the relationship that you have with your parents”*. An example of an interview schedule is included in the Appendix. Interviews were recorded and I made field notes immediately afterwards concerning any non-verbal communications such as posture, hesitations and the respondent’s ability to retrieve information and articulate their experiences (Fade 2004). This non-verbal and contextual information enabled me to interpret the meaning of the experience for the interviewee with greater insight.

Data analysis

Interviews that took place in February/March 2010 were transcribed verbatim by me, including pauses, repetition and laughs which helped me to interpret the meaning of the experience for the interviewee. Subsequent interviews were transcribed by a professional transcriber so I could devote my time to interpretation and analysis rather than transcription. Each transcript was analysed in turn according to the process illustrated in Figure 6.

Stage 1: Data immersion

In order to immerse myself in each individual’s narrative and become completely familiar with the content I read each transcript several times whilst listening to the audio recording. Imagining the voice of the participant during subsequent readings is reported to help the researcher to make a more complete analysis (Smith, Flowers and Larkin 2009). Making notes about my recollections of

the interview experience and my first impressions on reading the transcript helped to put my fore-thoughts to one side before the more focused process of active engagement with the data.

I next printed out transcripts with wide margins to the right (for noting exploratory comments) and left (for recording emergent themes). Paragraphs were numbered for subsequent ease of locating themes/quotes within the data.

Stage 2: Text analysis

The first level of analysis involved making exploratory notes and comments. Some comments had a more descriptive focus, reflecting key issues of concern (such as events, relationships, processes, values and interests) to the participant. I highlighted significant phrases in the text and noted comments recording the emotional responses of the participant (and in some cases myself) to those issues. This enabled me to think about *“the participant’s experiences in terms of their relationship to the important things that make up their world”* (Smith, Flowers and Larkin 2009). Each re-reading of the transcript prompted the development of further descriptive and exploratory comments.

In some cases I researched dictionary definitions of a particular phrase or word used by a participant to explore hidden meanings. Callum for example said he had been *“assaulted”* at school. Dictionary definitions referred to the physical and emotional impact of an *“assault”*, emphasising the significant impact of the event. Focusing on the language used helped me to understand the context and meaning of the events, relationships and processes for each participant.

Text analysis also involved questioning and exploring interesting features of the participant’s accounts to develop a series of conceptual comments. Tentative links were made between parts of the transcripts as an understanding of the participant’s experience as a whole emerged from repeated readings. This process involved moving away from the participant’s actual words to develop an overarching understanding of the issues of concern to the individual. Homework emerged as a strong theme for Ian and was a subject that he returned to frequently. Examining Ian’s transcript as a whole allowed me to conceptualise homework as an ‘impossible task’ showing Ian’s frustration at his inability to represent himself adequately on paper. Ian anticipated his teachers would not recognise the time and effort he invested and that he would not receive the mark for his work that he felt he deserved. Drawing on my personal experience and professional knowledge as an occupational therapist allowed me to reflect on Ian’s words and to conceptualise what homework meant to him. This process of analysis, described by Smith et al (2009) as Gadamerian dialogue, opened up the possibility of additional meanings for further exploration.

Stage 3: Theme development

For this stage of analysis I focused on discrete parts of the transcript whilst simultaneously taking account of what was learned throughout the whole process of text analysis to develop a list of emergent themes which summarised participant's words and my interpretation of them. Figure 5 is taken from my analysis of an interview with Ian in which he described struggling to cope with task demands in the classroom, and illustrates the development of emergent themes.

Figure 5: Extract from a transcript illustrating theme development

Emergent themes	Transcript	Exploratory comments
An impossible task Disengagement	If it's something impossible then I'll lower the standard a bit, I just sort of tell myself that 'I don't know how to do this' and I won't ask the teacher.	Frustration. Sense that the task is too hard. Despair, giving up. Protecting himself – defensive. Response to previous failure experiences?

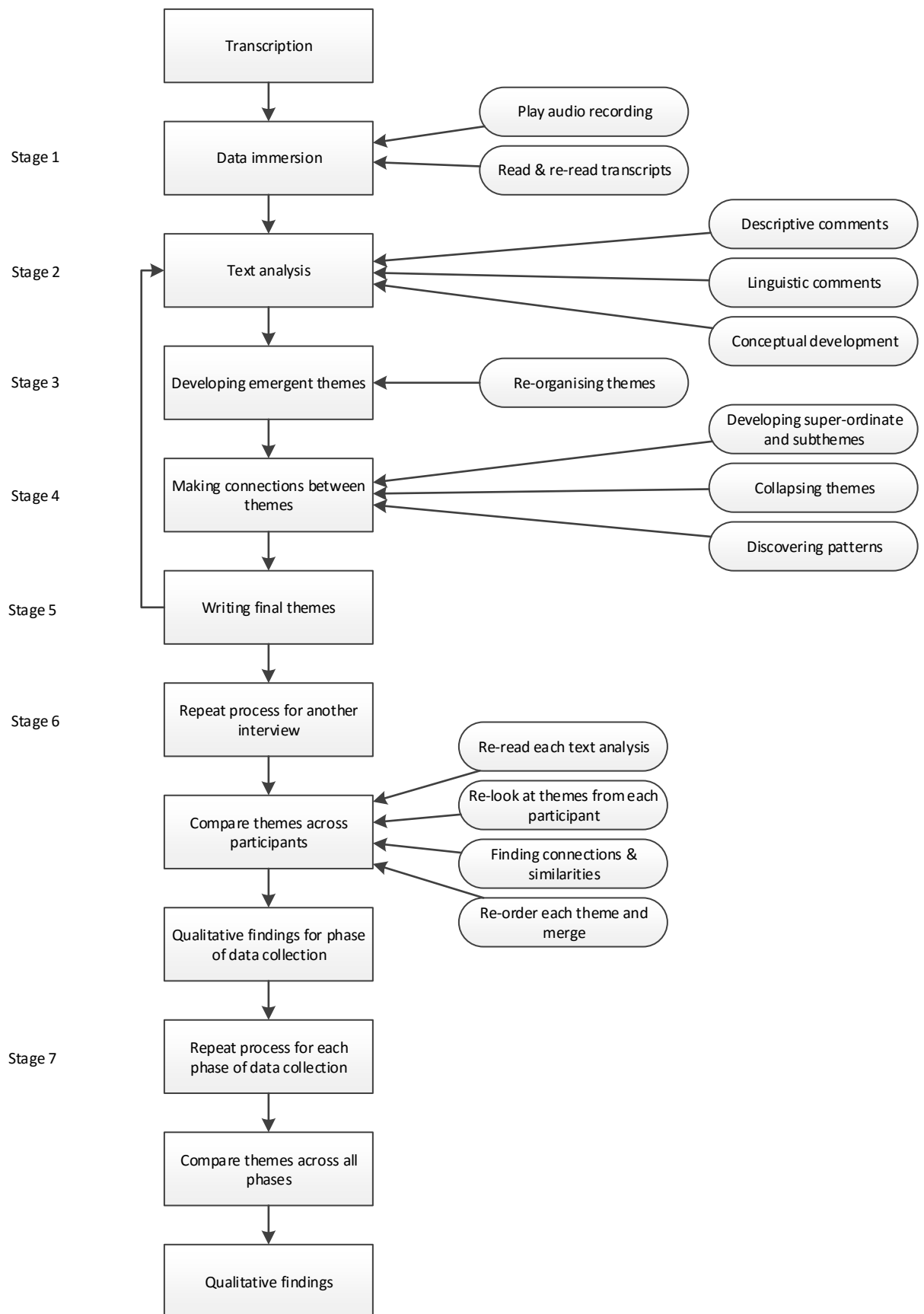
Stage 4: Making connections between themes

Next I listed all emergent themes and looked for patterns and connections between them, reorganising, clustering, collapsing and drawing themes together to represent what I felt were the most interesting and important aspects of the interviewee's account. To ensure that themes were firmly grounded in the participants' narratives, I then returned to the original transcript. Significant comments and phrases were "lifted" from the transcript, cut out and pasted onto individual cards. These cards were laid out on a large space, re-organised, moved around and once again arranged into thematic groups. This process helped me to review the emergent themes, identify new connections and feel confident that the themes truly reflected the participants' experience.

Stage 5: Writing final themes

Following this process, a list of master themes was developed for the participant with subthemes under each one. These were recorded in a table, linking themes to a transcript paragraph that provided a good example of the source material. Themes that did not fit into the established master themes for an individual were noted in case they were raised by other participants and developed greater significance later on during the analytical process. I then produced a brief narrative analysis (a case study) of each participant's experience to capture the meaning of the experience of being a teenager with DCD/dyspraxia for that individual.

Figure 6: Diagram illustrating the analytical process



Stage 6: Moving to the next case

After each transcript had been analysed according to the process described above, themes were compared across cases and a table of master themes for the group constructed. Themes were not selected on the basis of their frequency of occurrence between cases, but on the power of their expression and the extent to which they illustrated the experience as a whole (Buetow 2010).

Stage 7: Analysis of 'whole group' findings

The above process was followed for each of the three phases of data collection following interviews with individuals aged 13, 14 and 15 years. At the end of this process master themes from all phases of data collections were reviewed and checked for their convergence and divergence. This resulted in further reconsideration and modification, leading to the development of a master-list of themes that illustrated the experience of living with DCD/dyspraxia as a teenager as a whole. Throughout this process, reference was made back to individual case studies and transcripts to ensure that themes were firmly grounded in participants' own words.

Analysis continued throughout the research process and was informed by discussions with members of the Reference Group, meetings with my supervisory team and reflections during my clinical practice. Analysis also continued during the 'writing' stage when further reflections prompted new insights. Frequent reference was however made back to the original transcripts to ensure that analysis was firmly rooted in participants' accounts. Analysis was drawn to a conclusion when I felt satisfied that the essence of the experience of living DCD/dyspraxia as a teenager as articulated by participants had been revealed.

Reflexivity

Reflexivity is an essential part of IPA and is the process by which the researcher reflects on and considers the intersubjective dynamic between themselves and the data (Biggerstaff and Thompson 2008, Finlay 2003). Rather than attempting to reduce the researcher's influence, IPA acknowledges and explores the researcher's role, incorporating this positively into the analytical process and theory development (Cronin-Davis, Butler and Mayers 2009). I captured my thoughts and feelings in a research diary throughout the IPA process (Smith, Flowers and Larkin 2009), recording these as explicit and legitimate parts of the enquiry. Consequently, my introduction to this thesis, and the analysis and discussion that follow, represent an integration of my perspective as an occupational therapist, as a mother of teenagers and as a volunteer with the Dyspraxia Foundation. I also acknowledge the influence of the Reference Group on my interpretation, and highlight this specifically when discussing one of the master themes in Chapter 5.

I adopted an intersubjective reflective approach, focusing particularly on the emotional investment in the relationship that I had with my participants (Finlay 2003). My research diaries reflect my emotional responses to the frustration, anger and disappointment experienced by participants that I also see in my practice as an occupational therapist and as a volunteer with the Dyspraxia Foundation. These emotional reactions provided additional insights, helping me to better understand the vulnerability, frustration and in some cases the optimism experienced by teenagers with DCD/dyspraxia. For example, my anger that participants were denied access to the support that would enable them to be successful at school helped me to see in a new light the disempowerment that teenagers with DCD/dyspraxia experience when organisational solutions hinder, rather than facilitate their school performance.

I also used my research diary to capture and explore the influence of the Reference Group on the analytical process. In one entry I reflected on Dawn's emotional reaction to an interview quote which highlighted the cumulative impact of teachers' negative comments and low expectations on a participant's self-esteem and hopes for the future. Dawn's reaction enhanced my understanding of participants' sense of hopelessness and feelings of underachievement when their difficulties and potential went unrecognised. Reflecting on my reaction to members' responses therefore added depth and insight to the analytical process.

In addition to my written reflections, an on-going process of verbal reflexivity occurred throughout the inquiry process during supervisory team meetings and when discussing my research and preliminary findings with colleagues, fellow researchers and members of the Dyspraxia Foundation. Pondering on these discussions, often when driving, revealed further insights. In summary, adopting a reflexive approach enabled me to address the subjectivity inherent in qualitative research. It also provided a tool with which to enhance and improve the quality of the research by adding depth and insight to the analytical process.

Credibility and trustworthiness of findings

Various strategies were used to ensure credibility and trustworthiness of the study so as to demonstrate that the findings offer a plausible account of the lived experience of teenagers with DCD/dyspraxia. Strategies included member checking, transparency about the research process, adopting a reflexive approach and working with a research Reference Group. Each of these strategies is examined in turn.

Interview summaries were sent to each participant to check the accuracy of the data that was collected. Although interviewees are often sent whole transcripts to check for accuracy, the Reference Group advised that teenagers were unlikely to read a long document. Although

participants were invited to forward any further thoughts or comments, disappointingly only one participant responded to clarify a point.

Throughout this chapter I have attempted to make transparent the research process. Smith et al (2009) describe this as providing an audit trail that allows others to assess a study's quality and utility. Further reflections on the methodological strengths and limitations of the study and their impact on the trustworthiness and credibility of findings are included in Chapter 8.

I have been conscious of the influence of my personal experience, values and preconceptions throughout the analytical process. Use of a research diary and field notes made immediately after each interview and Reference Group meeting captured my feelings, concerns and interpretations. These allowed me to acknowledge and consider my preconceptions and biases and their impact on the research. As a clinician for example, it was difficult for me to hear David's comment that occupational therapy was "*a waste of time*" because he hadn't noticed any improvement in his handwriting following intervention. I was disappointed that David's experience reflected badly on my profession; further analysis however, led me to understand that David's comments reflected a wider frustration at his inability to improve his writing despite trying hard; increased effort, not specifically occupational therapy was a "*waste of time*" because it did not lead to an improvement in skills. Referring to my reflective accounts and interview transcripts throughout the process of analysis therefore helped me to recognise interpretative biases arising from my personal experience and ensure that my interpretation was firmly grounded in the data.

Working with a Reference Group enhanced the credibility and trustworthiness of this study by ensuring that the study was meaningful and that interview questions were relevant to the teenage participants. Furthermore, as discussed in Chapter 3 involving the Reference Group in the analysis helped to address issues of power that occur when a researcher interprets others' stories. Involving the Reference Group also allowed me to check my understanding and interpretations to ensure that my reporting of participants' experience was accurate. I felt a strong responsibility to ensure that I represented accurately the voice of teenagers with DCD/dyspraxia whose voice is rarely heard. Developing a shared understanding of the findings therefore resulted in a broader and deeper analysis than I would have been able to develop as a lone researcher with a background in occupational therapy.

Conclusion

This chapter details the research methods used including descriptions of the methods adopted to recruit participants, the interview techniques employed and the complex process of analysis. I described the approach taken to ensure the trustworthiness and credibility of the study, including an

examination of my influence as a researcher on the analysis. A critical analysis of the methodology in terms of its credibility, transferability and methodological limitations is included later in Chapter 8. The following chapter moves on to present the key themes derived through the process of interpretative phenomenological analysis. Quotes are used throughout to support the interpretation of findings.

Chapter 5

Findings

Chapter 5: Findings

Chapter 4 detailed the process of enquiry used to further understanding of the lived experience of teenagers with DCD/dyspraxia. The philosophical underpinnings of IPA were introduced and the research design described. In Chapter 3 the role of the Reference Group was examined. Throughout previous chapters the influence of the philosophical underpinnings of IPA and the Reference Group on the conduct of the research has been detailed. This chapter moves on to explore key themes that emerged from the study to provide an in-depth understanding of the lived experience of teenagers with DCD/dyspraxia from their own perspective.

This analysis evolved through a close reading of participant's accounts. In the following sections the participants' voice is prioritised and is presented without reference to the extant literature as to do so risks diluting or suppressing the voice of a group whose experiences are marginalised in the dominant discourse (Smith, Flowers and Larkin 2009). Later, in Chapter 6 participants' experience will be placed within a broader theoretical context and in Chapter 7 a conceptual framework will be presented as a way of making sense of the whole. This chapter therefore, reveals the researcher's interpretation, informed by the insights of the Reference Group, about how teenagers with DCD/dyspraxia make sense of their lived experience, drawing together the insights and concepts that recurred across accounts to present a gestalt of the experience of living with DCD/dyspraxia as a teenager.

In accordance with IPA methodology, participants' quotes are used extensively. To ensure narrative coherence, any editorial elision is indicated by three dots (...) and repeated words and utterances such as 'erm' and field notes regarding non-verbal communication have been omitted unless specifically relevant to the interpretation. All information that could potentially identify the participants has been omitted, including geographical locations and names of schools. Pseudonyms are used to ensure the anonymity of siblings, teachers and therapists.

Following the in-depth ideographic, inductive and interrogative process of analysis, five main themes emerged. Themes are illustrated by quotations as a way of prioritising the participants' voice, but where a suitable quote could not be found I have chosen a title that captures the theme content.

Themes are:

- *"Doing everything the hard way."*
- *"I didn't want to be seen as someone different."*
- *"Don't get me wrong, I'm an intelligent person but I can't even write. It's making me fill up"*
- Right help, right time.
- Making sense of the diagnosis

Table 11 illustrates the master, secondary and subthemes that were revealed and that describe the lived experience of teenagers with DCD/dyspraxia. In the following section each theme is explored in turn.

Table 11: Themes, secondary themes and subthemes of the lived experience of teenagers with DCD/dyspraxia

No.	Master theme	Secondary theme	Subtheme
1	<i>“Doing everything the hard way”</i>	<ul style="list-style-type: none"> • Daily life as a physical challenge • Not just a physical construct 	
2	<i>“I didn’t want to be seen as someone different”</i>	<ul style="list-style-type: none"> • Standing out, not fitting in • Acceptance and belonging 	<ul style="list-style-type: none"> ○ Visibly different ○ Marginalised and excluded ○ Difficulties exposed ○ Socially vulnerable ○ Accepted and understood by family ○ Acceptance by peers ○ A sense of belonging
3	<i>“I’m an intelligent person but I can’t even write. It’s making me fill up”</i>	<ul style="list-style-type: none"> • Feeling stupid • Anger and frustration • Stressed and anxious • Coping 	
4	Right help, right time	<ul style="list-style-type: none"> • <i>“They don’t understand me and my ways”</i> • Disadvantaged by the system • <i>“I suppose it’s better than being in the hall and struggling with my writing”</i> • Involved and empowered 	
5	Making sense of the diagnosis	<ul style="list-style-type: none"> • <i>“I knew I was different from most other people”</i> • Being diagnosed • <i>“I don’t really know what it is”</i> • <i>“I can’t do much about it, that’s just who I am”</i> • Disclosure 	

Master theme 1: “*Doing everything the hard way*”

This theme represents participants’ perception of the effort required for them to successfully participate in everyday activities which they attributed to their diagnosis of DCD/dyspraxia.

Participants experienced a range of motor difficulties meaning they had to work hard to master and perform tasks that others took for granted. They also experienced a range of non-motor difficulties with organisation and planning which they also attributed to their diagnosis. Participants therefore experienced DCD/dyspraxia as hard work both physically and mentally; to them, DCD/dyspraxia was not just a physical construct.

Within this theme there is a particular focus on participant’s perceptions of the effort required to master and perform self-care activities, practical school subjects and handwriting as these were common and significant areas of concern. Focusing on these activities is appropriate because evidence that coordination difficulties significantly interfere with academic achievement and/or activities of daily living is essential for a diagnosis of DCD to be made, with poor handwriting given as a specific example (American Psychiatric Association 2013). This theme includes the following secondary themes:

- Daily life as a physical challenge
- Not just a physical construct

It should be noted that mastery and performance of everyday activities requires a combination of both motor and non-motor skills. This is reflected in George’s comment that it had taken him a long time to “*grasp*” the ability to tie his shoe laces:

George: There are some things which other people just get like that (clicks fingers), like tying my shoelaces or something like that, which took me a lot longer to grasp.

Tying shoe laces is a complex task requiring good manual dexterity and the ability to use two hands together (motor skills) plus spatial awareness and accurate sequencing of movements (non-motor skills), all of which may be a problem for people with DCD/dyspraxia. Whilst acknowledging the complex interaction between motor and non-motor skills required for successful task performance, for ease of reading, physical and non-motor challenges are presented separately.

Daily life as a physical challenge

By definition people with DCD/dyspraxia display a marked impairment of their motor coordination (American Psychiatric Association 2013) so it was not unexpected that participants felt they had to work hard to master and perform personal activities of daily living involving fine and gross motor coordination. Despite requiring more effort and taking longer to master activities than their peers

however, participants were usually able to perform activities with a similar degree of independence, albeit not necessarily to the same standard. By age 15, George had mastered getting dressed and brushing his teeth through repeated practice as part of his daily routine. He was however irritated that the outcome wasn't always quite as he hoped:

George: It is annoying sometimes, like I do buttons wrong on my shirt and stuff but when I've realised I change it. I used to wear laces but then I can do laces up but I prefer not to, I have slip-on shoes now. I can do laces up, it's just annoying having to do them all the time. But I think everyday things I've kind of learnt to overcome them...I think just with like practice ... you learn how to like put your shirt on, do your teeth and put trousers and stuff on from an early age so I think I've, obviously it's harder but then as I've grown up it's been, it's not a problem for me doing those things now.

While George had learned to manage many self-care activities independently he remained anxious that doing up his buttons wrong or not tying his laces properly would draw attention to his difficulties or cause problems such as being late for school. George and others felt that the time and effort required to master skills made it impossible to be competent in all activities of daily living; they coped by avoiding certain tasks (George and Harry wore shoes without laces for example) and by investing time and effort into mastering only those activities that were personally relevant and meaningful; Callum for example was motivated to learn to tie a tie because it was important for him to feel smart at church. Even when participants had mastered an activity their performance was not always commensurate with the amount of effort they put in and they were resigned to accepting an outcome that was 'good enough' rather than perfect:

George: It takes more effort and practice to get stuff not like perfect, but do stuff like to a standard that's OK.

Being unable to achieve a desired goal to the standard they hoped led to frustration and disappointment, an issue which is explored later in this chapter. Moreover, it seemed that continuing to have difficulty with basic motor tasks that younger children managed easily had a negative impact on participants' confidence and self-worth. Comparing themselves unfavourably to younger siblings reinforced participants' lack of competence and affected the natural order of sibling roles as younger siblings took on or were given responsibility for helping their older brother or sister; David for example, felt inadequate when his mum asked his younger sister to help him make his bed:

David: If I have to make my bed, she gets (sister) to help me do it and stuff like that. But I can't do it, that's the point.

By contrast, Billy appreciated the support of his sister who helped to organise his equipment and who introduced him to a different social group outside of school. Those with older siblings found them to be supportive, such as helping with homework or inspiring them with thoughts and ideas for the future. Adam for example thought he might go to university like his older brother, while Freya wanted to be independent and learn to drive like her sister.

David was aware that his motor difficulties placed demands on his Mum's time and patience which caused tensions in their relationship:

David: When Mum was teaching me to tie my shoes laces she don't take the time with me. She just shouts at me if I do it wrong or something. She gets stressed, she has to be patient with me, does that make sense? And sometimes she runs out of patience.

His Mum's frustration reinforced David's own frustration at his lack of competence. Participants' sense of frustration and embarrassment at having to rely on their parents for help at a time when they expected to be developing greater independence was shared by Reference Group members. Some however, felt their parents were over-protective and were irritated when they were not allowed to do things independently because their parents perceived the risks to be too great. David felt constrained by his Mum's fear that he would hurt himself:

David: My Mum doesn't like me using it (the oven) because of my hands. She thinks I'll burn myself. Same with the kettle. See what I mean about the freedom?

Failure to master seemingly simple daily activities had a significant impact on participants' sense of efficacy and inhibited the development of independence skills at a time when many adolescents expect to take greater responsibility for themselves. By contrast, when they did master even simple activities, participants felt an extraordinary sense of achievement: David described himself as "*glowing*" when he'd learnt to cut fish with a knife and thought his scones as "*actually quite amazing*". Likewise Billy felt a great sense of satisfaction when he managed to split logs for the fire which was a valued family activity:

Billy: The other day in the garden I was splitting some logs with the splitter. I would tap it in, get the sledgehammer and try and split them. And it took a while to get it right because I can't hit a nail in straight, let alone split a log, so the sledgehammer was hitting the side of the splitter. But after I did get it right it was working quite well, and I enjoyed it.

Poor motor difficulties affected participants' perceived competence and performance of practical school subjects. This was of increasing concern to them as task demands and performance

expectations increased at secondary school. By contrast, during the primary school years George's coordination difficulties had a much less obvious impact in the classroom because the range of abilities was much broader:

George: At primary school it wasn't like, okay I couldn't colour in and stuff, but then loads of boys can't. Then when I went to secondary school it was like, it got a lot harder for me to cope with, not cope with it but kind of like deal with it, like get around it and stuff.

The increasing gap between Georges' motor ability and the physical demands of tasks he was expected to perform caused him frustration, anxiety and disappointment. Concerns were heightened during compulsory design and technology lessons where participants' coordination difficulties were exposed to themselves and others:

Callum: Cutting with the saw, because it like goes all crooked and I can't cut it on a line.

David: Technology (*is hard*) because like it's all sawing and stuff like that. And it's accurate measuring and I haven't got any of that.

Participants struggled to use tools and equipment efficiently and accurately, especially when under time pressure or when working in a distracting environment. They were particularly anxious about the risk of injury when using hot or sharp tools. For many their fear was based on previous experience: Callum and David for example had both injured themselves because they were unable to hold their woodwork equipment steady. Participants were frustrated and disappointed because it was impossible for them to create a product of an acceptable standard; moreover, knowing that they would be judged by teachers and peers according to the quality of the product they produced reinforced their sense of inadequacy. David described the outcome of his efforts as "*terrible*" while Callum was upset because he had never managed to finish a project. An inability to use tools and equipment efficiently and accurately, the poor quality of the products they produced and frequent injuries reinforced participants' self-image as incompetent and accident-prone. Consequently George felt a great sense of relief when he was able to drop practical subjects in Year 10 as the burden of having to achieve and be assessed against unattainable standards of performance was removed:

George: I've dropped all the subjects I didn't like, like art or DT or music, and I'm doing things that I like and I'm like good at, so it feels a lot better.

By contrast, David had to continue technology lessons at school. Although initially anxious because of his perceived motor incompetence, his ability to handle tools and equipment improved as he

gained more experience and confidence. David's experience demonstrates that persisting with motor tasks with appropriate help and support can lead to skill mastery, increased confidence and resilience:

David: I used to be scared of using equipment and that, but now I'm alright, I was (*scared*) but I'm getting better now.

All participants were concerned about the impact of their motor difficulties on their academic performance as the pace of work increased over time. Billy described work in year 11 as "*reasonably sort of strenuous stuff*", highlighting the persistent effort required for him to maintain an appropriate level of performance as he progressed through secondary school. Poor handwriting was a particular cause of stress, frustration and anxiety because of the effort required for participants to produce an appropriate amount of legible work that reflected their abilities. Participants had to put more effort into the mechanics of handwriting than their peers which made it difficult to write both neatly and at speed. Freya coped by rewriting her work at home:

Freya: if I have to do like loads of writing in a short space of time then it's like, just do it quickly, and then it's really messy. And then I do it all at home (*laughs*).

Billy also put in extra time and effort at home to produce work of a standard that he expected of himself; however this reduced the time he had available for leisure and relaxation:

Billy: We're given between one to three pieces (*of homework*) per night and each piece is meant to be 20 minutes or half an hour long, but I ended up spending an hour or maybe even two hours on one piece. It was just taking most other people half an hour or at the most 40 minutes.

It was evident that deciding whether it was more important to prioritise the quality (legibility) or the quantity of their written work was a daily dilemma for participants; while they could achieve an acceptable standard of performance if they tried really hard it was impossible for them to sustain this level of effort at all times. Frequent decisions had to be made about where to invest their personal resources; these were influenced by the importance of the activity to each individual and previous experience indicating whether putting in more effort was likely to improve the outcome. Ian for example, had tried adapting his grip and style to improve the speed and presentation of his writing, but without success. His awkward pencil grip made it impossible for him to write fluently and led to discomfort and fatigue during long writing tasks:

Ian: It's the fluent sort of writing it out, I hold my pen really weird as well which doesn't really help, but I've got into the habit of writing at that angle... I always try to make it neater but it's never neat (*slight laugh*), so, I always revert back to the, to just not joined up but just normal writing and I suppose I just find it a bit easier and neater than if I did try to join up.

Ian felt disadvantaged because he lacked the motor skills to write fluently and legibly, yet putting effort into joining-up his writing did not improve legibility so he reverted to a simpler, printed style. Ian did not regard this as an ideal solution however, and the presentation and speed of his writing continued to be a source of frustration and disappointment to him and his teachers. Participants also withdrew effort in non-writing activities when they perceived that an increase in effort was unlikely to significantly improve their performance. Eden for example, avoided physical activity because he doubted his physical abilities, justifying his lack of engagement in PE by trivialising it and arguing that it wasn't important for his future career:

Eden: It (*PE*) doesn't help you like get any skills. Like if you want to like want to become a doctor you don't need PE to become a doctor, if you want to become a lawyer you don't need it to become a lawyer, you are not going to like play basketball in the middle of a (*court case*).

While avoidance of challenging practical tasks preserved participants' self-esteem by minimising the risk of failure, it also limited opportunities for them to develop skills and competence in activities which might be important for their future economic, health, emotional and social well-being.

Not just a physical construct

In addition to the extra physical effort required to carry out everyday activities, participants perceived that they had to contend with a range of extra non-motor difficulties compared to their peers. They considered difficulties with organisation, time management and attention to be common, shared features of DCD/dyspraxia:

David: I aint really good at organising myself, that's why mum didn't get me a phone. Like I lose my bus pass and that, and just not good, but I think that's to do with the dyspraxia isn't it? Organisation, I haven't really got any.

Feeling disorganised was a daily experience for participants and was associated with lost equipment, lost time and missed opportunities; members of the Reference Group confirmed this to be the case. Although Billy described the items that he typically misplaced as "*trivial*", losing them caused inconvenience, frustration and wasted time. Sometimes there were immediate negative consequences such as detentions or being grounded by parents. Some felt it unfair that their lack of

organisation was interpreted by others as carelessness or disinterest. Participants also missed opportunities to enjoy and participate in leisure and social activities because of their poor memory and organisational skills. Eden sometimes forgot to go to his youth club, while Billy had difficulty organising himself for Scouts which was frustrating and caused problems with others:

Billy: Sometimes I'm in trouble because I forget stuff... last year I turned up (*at camp*) without a sleeping bag, without a roll mat and the only thing I'd remembered was my torch, and so yeah, it didn't go particularly well! We had to go back and get the stuff which I think slightly annoyed my Dad... It's quite hard at Scouts because a lot of the time I do forget stuff and I think sometimes that's prevented me from doing some stuff.

While participants were irritated by the inconvenience that their poor memory and organizational skills caused, there was also a sense of disappointment at their inability to manage themselves and their equipment when others seemed to manage this intuitively. Billy was in awe of his Dad's organisational and planning skills and was frustrated at his inability to adjust plans and solve problems:

Billy: Dad came out and I was trying to split this log. And I'd been splitting them and throwing the logs behind me. And he said well "Well, after you've split them, put them in the wheelbarrow or put them on the pile because it means you don't have to move them twice", but I just don't think about that. I just, I end up doing everything the hard way, rather than doing it the easier, simple way that seems so easy.

At times participants felt overwhelmed by their inability to plan and strategize; the effort of putting an activity together sometimes seemed like a huge and impossible challenge. While they might have an image of what they wanted to achieve, it was difficult for individuals to organise their thoughts, ideas and actions into a logical order to achieve the outcome they wanted. This was of increasing concern as task demands and expectations increased during adolescence. Ian described the effort of "*putting the puzzle together*" to achieve a desired goal as "*a bit of a project for me*". Billy was similarly frustrated at his perceived inability to organise and structure essays during exams and worried that his academic abilities would be marked down as a result:

Billy: The arguments, although they're structured inside my head and I'll plan most of the points as I read the question in my head...it's getting that down and correctly and in a sense that someone else can understand how it works. I mean, to me it makes perfect sense, but to someone else it might not.

Ian acknowledged that having a clear plan increased his potential for achieving a satisfactory outcome; however he lacked the skills to develop and execute a plan in practice:

Ian: Having it all planned out I find is so much easier than having to think about it and that's what I find generally easier with everything, planning things, if you plan it out. I didn't do it in the exams though, but I mean just generally plan everything out, it's so much easier I find than having to rush it, improvise.

Ian knew that he needed to plan ahead to be successful, but wasn't able to do this consistently. He also struggled to process information and instructions quickly, creating a sense of disorientation and confusion when he missed directions or lost focus on a task. Being given a large amount of information at once or working in a distracting environment heightened anxiety about missing important bits of information, doing things in the wrong order or running out of time to complete a task. David struggled to attend to information and instructions, especially when there was a motor action involved:

David: I can't take instructions so I might have added the milk before doing something else, I might have cut too much or too little.

David's inability to follow instructions affected the outcome of his efforts. These issues were discussed by the Reference Group who identified a key point of frustration as participants' inability to allocate attention appropriately which meant they were unable to achieve tasks as they hoped or expected. Eden for example, found it hard to organise himself and his actions when in a busy environment with many demands on him physically and mentally. His repetition of the phrase "*I keep*" implies that these were repeated experiences and suggest that he found it hard to learn from previous mistakes:

Eden: I keep getting off at the wrong stop and I keep forgetting which bus it is to get back here.

Eden was frustrated and puzzled by his inability to recall his bus route even though he travelled frequently and tried hard to remember. Some participants seemed to cope with their poor memory and organisational skills by 'over-compensating' or being super-prepared, a coping strategy described by some adults with DCD/dyspraxia that I have met previously. David for example, carried all his school books with him every day, while Billy was somewhat obsessive about organising his bookshelves:

Billy: With my bookcase upstairs I try and organise it into subjects and series, and the series into authors almost, and I'd enjoy organising it. It's just something that I struggle with.

Billy's satisfaction at being organised in one area of his life was however in stark contrast to his experience at other times. His description of his organisation as "*up the creek*" indicates a sense of powerlessness at finding himself in awkward situations because of his poor organisation.

Participants relied heavily on routines to help them feel in control; however they struggled to establish new routines and to adapt when plans changed, for example at the weekend or during school holidays:

Harry: I find I need a routine but I find it hard to follow the routine.

Harry struggled to develop routines for himself and found it hard to adapt during the school holidays, an experience shared by some members of the Reference Group. However he found the familiarity and predictability of routines reassuring as they helped to reduce the risk of misplacing items, forgetting to do things or running out of time.

Summary of master theme 1.

The master theme "*Doing everything the hard way*" demonstrates that participants had to put in more effort to master and perform home, school and leisure activities compared to their peers. Moreover, they perceived DCD/dyspraxia to be not just a physical construct, as organisational, attention and time management problems also affected them on a daily basis. Participants coped by prioritising certain activities on which to focus their time and effort, whilst by avoiding other tasks. Participants were frustrated that they were unable to perform to a consistently high standard. There was however a sense of optimism and hope fostered by their experience of learning to master and cope with activities that they had once found difficult:

George: It's obviously going to take a lot of work or practice and I know it (*dyspraxia*) can't really be cured, but there's a way of managing it and that's what I wanna try and do, and it's always gonna affect me, but you've got to sort of try and control that.

Master theme 2: *“I didn’t want to be seen as someone different”*

The master theme *“I didn’t want to be seen as someone different”* focuses on the impact of DCD/dyspraxia on participants’ relationships with peers, close friends and family members (in this context the term ‘peers’ refers to people of a similar age to participants who were not necessarily their friend). This theme explores teenagers’ perceptions of how others viewed them, highlighting their fear of being ‘different’ and the tensions arising from their desire to fit in and be accepted. Participants felt pressure to conform and were anxious when coordination and communication difficulties affected their participation in certain contexts. Some had experienced bullying and social exclusion. All however identified social groups where they felt a sense of acceptance and belonging, and all identified close friends and family members who provided them with practical and emotional support. This theme is divided into the following secondary themes:

- Standing out, not fitting in
- Acceptance and belonging

Standing out, not fitting in

This secondary theme explores participants’ sensitivity to factors that might make them stand out as different from their peers. Participants were anxious about being visibly different and feared that they would be marginalized or excluded because of their perceived inadequacies. They were particularly concerned about using alternative equipment because this risked highlighting their differences, even if it did enhance their academic performance. Participants worked hard to avoid drawing unwanted attention to themselves, but some still felt socially vulnerable and had been the victim of bullying. The findings relating to the secondary theme ‘standing out, not fitting in’ are organised into four sub-themes:

- Visibly different
- Marginalised and excluded
- Difficulties exposed
- Socially vulnerable

Visibly different

George felt strong pressure towards conformity, wanting to fit in and be seen as part of, rather than apart from his peer group. He was concerned that his coordination and organisational difficulties were obvious and affected others’ perceptions of him:

George: I don’t wanna like stand out as much, I just want to be like a normal person and obviously I know that sounds a bit bad, but I just didn’t want to like be seen as someone different.

George worried that his peers would be reluctant to associate with him because of his perceived inadequacies and that he would become socially isolated; he was therefore reluctant to use different equipment or to participate in activities which might expose his difficulties. David was similarly concerned about standing out because of his poor coordination and was embarrassed by his inability to use cutlery at school which was something that he saw others managing easily:

David: Everyone knows that I struggle with my handwriting, but things like I can't use a knife and that is just, it just looks embarrassing.

Difficulty handling cutlery was a very visible sign of David's difference and he was embarrassed that others would think him stupid because of his coordination difficulties. Having difficulty performing developmentally appropriate activities was an increasing concern to participants as performance expectations increased and the gap between their performance and that of their peers became more obvious over time. Participants' fear of standing out was also affected by the context in which activities took place; for example while David was anxious about using cutlery when eating in public, he was less anxious about his handwriting difficulties as they were apparent only to his classmates who knew him well and would, he hoped, attribute his handwriting difficulties to DCD/dyspraxia rather than a lack of intelligence. Billy's social confidence and fear of standing out was similarly affected by the context in which activities occurred. While he was happy to play football with friends who understood his coordination difficulties, he was reluctant to play with people that he didn't know well, anticipating that this would lead to humiliation and rejection:

Billy: If it was a team sport with people that I didn't know particularly well, then I wouldn't particularly want to get involved in case I got it wrong.

Billy avoided playing football at break times because he was anxious about being rejected for letting his team down. This monitoring of performance and context was mentioned by other participants who spoke of carefully ensuring that their coordination difficulties were not obvious to avoid the stigma of being different.

All participants identified situations where their poor motor skills made them stand out. For Ian however, communication difficulties were an additional concern, affecting his social confidence and interactions:

Ian: It's just the way, as things come out, it's kind of jumbled, words aren't sometimes in the right order and (*slight pause*), and just sometimes things that you do say are, can just be like completely random than to what something normal might be...small chat, I suppose you can't do that as well, you just wouldn't really know what to say and when you do say

something it's not really as good ... it's not something you'd say normally in that kind of situation.... you feel it's a bit '[*inhales*] oo, a bit, 'why did I say that?' kind of 'cos you're kind of hoping to make the impression that's good, a good impression, and you're hoping you said the right thing but when it comes out you're a bit, 'was that, was that really a good thing to say?' ...What I do is to bring up something that happened a long time ago and then use it, and then say it 'cos I know I won't get that mixed up because I can remember what happened and say it.

It was apparent from Ian's verbal and non-verbal communication during this interview that it was difficult for him to process language quickly and his comments reveal that he was aware of these difficulties. Ian was anxious that he seemed "*weird*" to others because his responses didn't always make sense and that others therefore judged him as less able. Ian felt disadvantaged socially, finding "*small chat*" particularly challenging because he struggled to keep pace with fast-moving conversations. In order to 'fit in' with peers he therefore tried to steer conversations to familiar topics so that he could anticipate what might be said. While these strategies minimised the risk of saying the wrong thing at the wrong time they created further social disadvantage as Ian avoided interactions with unfamiliar people, preferring to socialise only with people he knew well.

Marginalised and excluded

Participants' coordination and communication difficulties created tensions with peers when they were expected to work together and in some cases this led to participants feeling side-lined or excluded from activities. Eden described how a classmate would not let him build any models because the ones Eden had made previously were poorly constructed:

Eden: I tried to help earlier but I wrecked everything, so he won't let me do anything that involved making characters...it like broke and we had to remodel everything...he was quite angry.

Eden felt his partner was angry because their models were ruined and had to be remade because of Eden's coordination difficulties. Eden thought he was excluded because his partner didn't want to be embarrassed in front of his class by creating a poor model: his partners' actions however, reinforced Eden's poor self-efficacy for constructional tasks and affected his willingness to engage in cooperative activities in the future. Billy also felt marginalised by certain individuals whom he felt didn't understand or weren't tolerant of his differences:

Billy: There's a couple of people in the group that are a bit sort of iffy around me I think. I don't know, but they've just got a bit of a bad temperament really, they are hot-headed and

if you frustrate them or, it happens to anyone really, anyone in the group they could just fall out with. But there you go.

Billy acknowledged that he was not alone in being marginalised by these people, but felt disadvantaged because his unintended behaviour evoked feelings of frustration and irritation in them. His use of the phrase “*there you go*” implies a resigned acceptance of being side-lined by these individuals; as demonstrated in the next section however, having a group of friends who understood and accepted him protected Billy against the negative reactions of peers who were less important to him.

A number of participants identified the distance between their home and school as a physical barrier to their social participation. Several attended a school away from their home which had been chosen in preference to their local school because it would better meet their learning needs. However, this limited opportunities for them to participate in leisure activities with school friends during evenings and at weekends because they didn’t live nearby. Participants therefore felt excluded from formal and informal social interactions by factors indirectly associated with DCD/dyspraxia.

Difficulties exposed

Participants’ sensitivity to factors that might make them stand out as different to their peers was highlighted by their concern about using alternative equipment at school. David was embarrassed and annoyed by the unwanted comments and questions he received when using a laptop in class:

David: I have a laptop but I don’t use it, it’s embarrassing... Everyone takes the mick out of me for it...they don’t tease me, they just don’t like me using it. (*In a teasing voice*) ‘Ah, David’s got this, David’s got that’ and they start moaning, asking me why I use it and that. And I just don’t like it... They just says ‘Why have you got that laptop? You are using your hands fine’. And I’m too embarrassed to say in front of everyone that I’ve got dyspraxia, because soon the whole school will know. And it will go round like that I’m some sort of disabled mongol.

David was embarrassed when classmates questioned why he was using the laptop because this forced a decision about whether or not he should disclose his diagnosis (concerns about disclosure are considered elsewhere in this chapter). He thought some people perceived the laptop offered an unfair advantage, while others saw it as a sign that he had special needs which was not the image of himself that he wanted to portray. Fear of being stigmatized by specialist equipment also led David to reject the scissors and writing tools suggested by a specialist teacher because he was ashamed about being associated with students who were less able than himself:

David: I don't want those things because they were really embarrassing and they were really noticeable. It's the sort of things that I don't want to use like. Does that make sense? Like the special people use.

Socially vulnerable

Some, but not all, participants in this study felt socially vulnerable and had experienced bullying and harassment by peers. David was teased because of his coordination difficulties:

David: Some kids say like I've got spacky hands and that's some kids that I don't like, and it kind of affects me and that, but I just get on with it, there's nothing I can do about it... Someone starts on me, I just have to knock them out man. Someone starts and just keeps jabbing on, annoying like, winding me up. They know how to wind me up.

David was embarrassed that he was associated with a stereotype that did not match his self-image and was angry that some people chose to amuse themselves at his expense. David recognised that he was sensitive to provocation but was unable to control his reactions. Sometimes his reaction caused him to get into trouble, further highlighting his vulnerability and difference. As David's self-awareness and confidence grew over time however, he was better able to disregard and reject comments by peers whose opinions he didn't value. Callum has also been picked on because his attitude to learning was different to that of his peers:

Callum: Someone assaulted me in the computer room in IT, I just said 'go away' and then he just attacked me... I was trying to work, he wasn't even working like, and he just kept disturbing me.

Callum tried hard to avoid drawing attention to himself by keeping a low profile at school. He was therefore extremely upset and distressed by the assault as it was an active sign of rejection whereas previously he had been ignored or scarcely noticed by his peers. Callum felt vulnerable and exposed following the incident: over time such feelings could have long-term implications for his self-esteem, confidence and emotional well-being. While Callum attempted to keep a low profile, Billy sought to actively influence others' impression of him by developing his skills as a rugby player, an activity that was socially valued by his peers. At age 14 however, he was losing his previous passion for the sport:

Billy: Rugby is something that I really don't want to do and not necessarily because I'm not in the mood, but it's something that I don't necessarily enjoy, but I force myself to do things I don't want to do but I want to be able to say to people that I do do.

Billy continued to play rugby because it gave him credibility among his peers and enhanced his social status. He regarded rugby a social currency and a means to peer acceptance and friendship; however his participation was at the expense of his personal enjoyment and satisfaction. All participants felt pressure to manage their image with peers, particularly with people who didn't know them well:

George: I get anxious, kind of how people will look at me, how I look and stuff at school, but I'm not like, obviously I want to look good at school, you know, no-one really wants to go to school looking like an idiot, then like I'm not overly fussed about how people are viewing me.

George's comment illustrates the tension between not wanting to stand out "*like an idiot*" and wanting to be accepted for himself. His account indicates that he was aware of a potential discrepancy between how he viewed himself and how he was viewed by others; as his sense of identity developed over the course of the study however, he became less bothered about others' perceptions and more confident and accepting of his differences. The importance of acceptance and belonging is explored in the following section.

Acceptance and belonging

A desire for acceptance and a sense of belonging was evident throughout participants' accounts and being with people who liked, valued and respected their personal characteristics increased their sense of self-worth (in this context 'self-worth' is defined as an individual's global sense of their performance abilities). While participants' coordination and organisational difficulties frequently caused tension at home, parents provided a safe environment in which they could be themselves without feeling judged. Outside the family, some participants felt more accepted by people who had special needs themselves, although conflicting needs caused tensions in their relationships at times. A sense of belonging was enhanced by sharing interests and experiences with peers, while close friends who accepted and valued participants' individual characteristics provided practical and emotional support. The findings under this secondary theme are organised into the following sub-themes:

- Accepted and understood by the family
- Acceptance by peers
- A sense of belonging

Accepted and understood by the family

Here the importance of family members by whom all participants felt accepted and understood is highlighted. While many participants struggled to make sense of their diagnosis (a theme which is explored later in this chapter), all felt reassured that their parents, in particular their mothers, were knowledgeable about their condition and valued their personality and characteristics despite their difficulties. Ian felt reassured that his parents understood that there was a reason for his behaviour and that he wasn't being deliberately naughty or emotional:

Ian: My Mum, well I suppose she's a bit relieved to find that after these years that there's something to cause for all these tantrums and wailing and behaviour and things like that... And I suppose my Dad's just, he just sort of acknowledges that it's there. But I know I can rely on them and that they're my parents, I can rely on them.

Ian's comments suggest that receiving a diagnosis was a turning point in his relationship with his parents because it meant they were able to understand and accept his behaviour; as a result he regarded home as a place where he could safely express his frustration and anxieties without embarrassment. Ian was confident that his parents would support him despite the tensions and arguments his behaviour caused because it was their role to be loving and supportive. By contrast, he did not feel understood and accepted by his teachers, a perception explored elsewhere in this chapter.

Like Ian, George felt close to his parents because of their shared experience of coping with DCD/dyspraxia and his other health needs. However, George recognised that his disorganisation and poor concentration created tension at times:

George: My Mum and Dad, they obviously know everything about the condition so we've got a good relationship but it can sometimes be hard because there's like a line for me between being caring and annoying ... my Mum she wants the best for me and so does my Dad ... but they can sometimes kind of like make a deal out of everything... it's quite stressful sometimes, leading to arguments with Mum and Dad.

George drew strength from his parents' acceptance of him and their belief that he was capable of becoming independent and achieving academically. Despite this however, he was frustrated and annoyed when they pushed him to study or to help out with family chores.

As illustrated by Ian's comments above, some participants felt that their father did not share the same level of understanding about their condition as their mother and were therefore less accepting

or tolerant of their problems. Billy's father had difficulty understanding his coordination and organisational difficulties which were obvious when they were carrying out a DIY project together:

Billy: When I try and help him I think it frustrates him a bit because he tries to get on with stuff and I'm almost a hindrance, so I think it's taken him a while to adjust to the fact that I am so different to them (other family members) in quite a few things.

Billy's father had difficulty understanding his difficulties because he was so different from himself. Billy however regarded his father as a role model, choosing to participate in certain activities to "*make him proud*". Over the course of the study however, Billy expressed a sense of growing understanding and acceptance by his father of his personality strengths and characteristics which was enhanced by their shared interest and experience in academic and leisure activities. For others however, a father's lack of understanding and acceptance was exacerbated by his absence from the family home. Freya for example, felt awkward when her Dad struggled to judge how much help she needed, but was reluctant to tell him what she could and couldn't manage for fear of upsetting him:

Freya: He'd like expect me to know like things and he'd be more thinking that I need loads of help. And sometimes he'd be like thinking that I don't need any help. So it's a bit like one minute he wants to help me and do everything for me, and the next minute it's like he can't do anything for me.

Participants generally felt that their siblings accepted and were aware of their coordination and organisational difficulties, even though they did not necessarily understand their diagnosis. Several acknowledged that difficulties associated with DCD/dyspraxia meant their siblings had to cope with many additional challenges including emotional outbursts which were caused by anxiety and frustration. George's relationship with his sister was close and supportive:

George: We fight quite a lot, but then like quite a lot of brothers and sisters do. She knows about dyspraxia and, you know, she's good, she puts up with a lot... I can be quite angry and bad-tempered towards her, she puts up with a lot but then she does give as good as she gets, you know? She can be horrible to me sometimes. I think we have a good relationship, like we know each other and we're quite close to each other when we want to be... I mean she does know a lot about the condition, she has to and I think she's quite like in tune with what's going on around her and stuff.

George felt that his sister cared about and accepted him, despite the tensions and challenges that his coordination and organisational difficulties caused at home. George's comments indicate that he appreciated his sister's tolerance of his difficulties and valued her tacit understanding of his

differences. While participants felt that siblings had an implicit understanding of them that was developed over many years, they also identified that others with additional needs were more accepting because of their shared experience of being different. This is explored in the following section.

Acceptance by peers

In this subtheme, I examine participants' perceptions of social acceptance by peers. Some participants perceived peers with additional needs to be more understanding and accepting than peers without additional needs because of their shared experience of being different, as illustrated by George's comment:

George: One of my best friends he knows what it (*dyspraxia*) is and one of my neighbours down the road has got an autistic older brother and he knows what it is... some of them that's like dyslexic or got other problems, I think are more understanding of it.

George perceived that peers who had 'insider knowledge' of special needs through personal or indirect experience were more supportive and understanding. There was a sense that George could relax and be himself when in the company of people with additional needs as there was less risk of embarrassment should his difficulties be exposed. The importance of being understood and accepted was highlighted by George's excitement at the possibility of joining a cricket club for people with additional needs:

George: The leader guy I've already talked to a few times and everything, and I have already mentioned my dyspraxia but he's like, they're all really nice and like obviously they know everyone's got a special need.

Feeling understood and accepted was also important to Harry whose rejection by peers and teachers at a previous school had had a devastating impact on his social and emotional well-being. Now attending a school for children with additional needs, Harry felt accepted and understood by his peers, commenting that they treated him "*like I'm normal, like I'm one of them*". Feeling understood and accepted by peers was important for Harry's self-esteem and confidence. Accounts indicate therefore, that for some participants a sense of acceptance and belonging was enhanced by friendships with peers who shared their experience of being different.

Acceptance amongst participants' wider peer group was enhanced by friends who provided practical and emotional support. David's friends protected him from potential ridicule by helping him to handle tools and equipment in technology lessons so that he could successfully complete a project.

Likewise, Freya and Eden's friends helped them to understand or process information which meant that they didn't have to draw attention to themselves by asking for help:

Freya: Sometimes it's like hard to remember stuff. Like if the teacher explains something and I start to do it, then I think 'What am I doing again?' But like I sit next to most of my friends and stuff, so if I don't understand it they just explain it again to me... I've got a lot of friends so then it's not like, nobody's going to say anything 'cos it's just me sort of thing.

Freya's close social network prevented her from embarrassment and underachievement by providing practical support in lessons. Furthermore, belonging to a friendship group who accepted and valued her personal characteristics protected Freya from rejection by less understanding peers and gave her the confidence to brush off attempts to discredit or embarrass her. David likewise felt protected by friends who spoke up on his behalf when he lacked confidence to speak out for himself:

David: They both stick up for me when I'm down. They'll stick up for me and I appreciate that. Say like when teachers like say I can't use it (*laptop*) they'll say 'Actually Miss, he's got this note in his bag' and like, 'cos I'm too shy to say that.

David felt that his friends recognised his difficulties and his potential for embarrassment which made him feel supported and enhanced his confidence. Likewise, Adam's friends supported him by helping to calm him down when he was provoked, reducing the likelihood of him getting involved in fights. What this finding reveals therefore, is that feeling accepted by close friends helped to protect participants from rejection by their wider peer group, enhancing their self-confidence and self-esteem. The following subtheme explores the factors that enhanced participants' sense of belonging.

A sense of belonging

While participants sometimes felt vulnerable within their wider peer group, all identified close friends who made them feel "*safe*" and with whom they enjoyed "*messing around, like in a group*" (Adam). Participants' sense of belonging was enhanced by sharing interests and activities with peers as this reinforced their similarities rather than their differences. Participants in this study tended to divide their leisure interests into 'sporting' and 'non-sporting' activities. I was interested to note that although DCD/dyspraxia is a movement disorder, several participants were motivated to engage in team sports because they enjoyed belonging to a team. While Billy, David, Ian and Freya invested a lot of time and effort in sports such as football, rugby and netball however, they were sometimes reluctant to participate in less formal situations where their coordination difficulties might be

exposed. While Billy was happy to play football with his friends, he had left a club after being ridiculed by his peers because of his poor performance:

Billy: It was too competitive. If you made a mistake everyone was moaning at you, so the team morale was terrible. I didn't enjoy it because if you did make a mistake you were teased endlessly. So I left.

Ian's experience was similar: although he was good at football, he felt like an outsider when other team members accused him of failing to pass the ball. So while participation in team sports promoted a sense of belonging for some people, it was evident that the context in which these sporting activities took place could have a positive or negative influence on participants' sense of acceptance and belonging.

Participants who identified themselves as 'not sporty' shared other interests with their friends; Eden's friendship group for example was united by a lack of interest in sport and instead shared interests in music, card games and Japanese comic art. Eden was keen to further establish his group membership by learning to play a musical instrument:

Eden: I started wanting to do music because everyone, all the friends that I know can play an instrument like quite well, at least like Grade 2 and so since I'm the only person who can't play an instrument I'll have to do one...I wanted to do piano because that sounded quite easy to learn, but two music teachers suggested that I do guitar and one of them suggested that I do bass because it's like guitar but apparently easier.

Eden was keen to play an instrument as this activity was valued by his friendship group; however, poor coordination made it hard for him to join in because he struggled to attain a similar performance standard. Participants' social confidence and sense of belonging was, however, enhanced by participation in social activities where there were few pressures to conform or perform to a particular standard. Billy for example, was an enthusiastic Scout where participation was valued over performance:

Billy: It's not set up to be overly-competitive, everyone gets on... when you do mess up or you bang into someone or spill the water out of the cup or something then it's alright. When you do make mistakes, someone's laughing, you do laugh, people laugh with you rather than at you.

It was apparent from Billy's accounts that his confidence and self-awareness developed over the course of the study; this finding is explored in more detail later in this chapter. What this subtheme

therefore reveals is that participants' sense of acceptance and belonging changed over time and was influenced by their choices and behaviours, as well as the response and reactions of others.

Summary of master theme 2

The theme "*I didn't want to be seen as someone different*" demonstrates the tension between feeling different whilst wanting to fit in and the pull towards conformity. Participants were concerned about the visibility of their coordination difficulties and the impact this had on their social acceptance. They were anxious about being stigmatized by peers who perceived them to be inadequate and worried about being marginalised by peers who perceived that their coordination and communication difficulties would have a negative effect on their experience of shared activities. Participants were particularly concerned about the reactions of peers who didn't know them well and coped by avoiding situations in which their difficulties might be exposed to minimise the risk of rejection. This strategy however, put participants at risk of social isolation by limiting their social networks.

All participants felt supported and accepted by family members and were able to identify peers who accepted, respected and valued their personal characteristics. People with personal experience of special needs were perceived to be particularly accepting and understanding. Feeling accepted and a sense of belonging was revealed to have important implications for participants' psychosocial well-being. The emotional impact of DCD/dyspraxia is the focus of the next master theme.

Master theme 3: “Don’t get me wrong, I’m an intelligent person but I can’t even write. It’s making me fill up.”

This third master theme ‘Don’t get me wrong, I’m an intelligent person, but I can’t even write’ represents the emotional impact of living with DCD/dyspraxia as a teenager. Participants felt inadequate when they were unable to perform tasks to a developmentally appropriate standard; their inadequacy was heightened when they compared their performance to others and when they did not reach their own performance expectations. Participants were frustrated by the impact of their difficulties and for some, angry outbursts compounded their problems. Others internalized their emotions, feeling anxious and stressed. Their emotional vulnerability was heightened by the reactions of others to their performance difficulties especially the reactions of teachers who participants felt should have greater understanding and empathy. Despite their experience of failure and frustration however, participants were surprisingly optimistic and positive about the future.

Within this master theme the following secondary themes emerged:

- Feeling stupid
- Anger & frustration
- Stressed & anxious
- Coping

Feeling stupid

Participants’ inability to carry out everyday activities to a developmentally appropriate standard made them feel stupid and inadequate. They were embarrassed that they struggled with activities that others managed easily, such as using scissors:

George: I’m never going to be like a good cutter or whatever, but it’s just, it just gets me down a bit.

George’s repeated experience of failure to master the use of scissors had a negative impact on his sense of competence which was reinforced when he compared the outcome of his efforts to that of others. He doubted his cutting ability and felt “down” when activities didn’t go well. Like George, David felt useless and inadequate when he compared his performance to that of his peers and younger sibling. By contrast, when he did master a task that he had previously found difficult, such as making his own bed, his sense of achievement and satisfaction seemed out of proportion to the task achieved:

David: it makes me feel good cos like it used to make me feel like I was not able, I was just worthless and that, but now it makes me feel good.

I was surprised at the strength of David's emotional reaction to both his failure and his achievement of seemingly trivial activities such as making his bed and pulling on socks, and feel it is important for professionals supporting teenagers with DCD/dyspraxia to understand the impact such difficulties have on self-worth and self-esteem.

Poor handwriting was a very visible sign of participants' coordination difficulties and a frequent reminder of their inadequacy. Comparing the presentation of his writing unfavourably to his younger sister also had a negative impact on David's confidence and sense of self-worth:

David: Oh just at writing, don't get me wrong. I'm an intelligent person, but like, I can't even write. It's making me fill up (*pause*). Don't know.

Interviewer: You're looking a bit down in your face when you say that. Does it make you feel a bit down when you see her writing a bit better than you do?

David: Yeah, yeah. It's just everything. She's better than me. Makes me feel bad about myself.

David was frustrated that his cognitive abilities were not reflected in his written work and worried that he would be unfairly judged by others as 'stupid' because his work was poorly presented. His self-esteem suffered because he was unable to project through writing the image he held of himself as a competent and intelligent student. Some participants sought to preserve their self-esteem by lowering their standards. When faced with a long writing task Callum adjusted his performance expectations by deciding to "*take a bit away*" so that he finished his work on time. This meant however, that he received lower marks for his work, reinforcing his negative beliefs about his academic ability. Likewise Ian downsized his expectations when faced with a cooking task that he perceived was beyond his capabilities:

Ian: If it's something impossible then I'll lower the standard a bit and I just sort of tell myself that 'I don't know how to do it'.

Resigning himself to a lower level of performance left Ian feeling that he had not reached his potential and disappointed that his potential would not be recognised by others. Billy sought to preserve his self-esteem by using humour and making a joke of the situation to influence the reaction of others to his difficulties. There was however an underlying sense that this strategy was not completely successful:

Billy: I find it quite amusing really, that I'm just so poor (*laughs*). You can just imagine it coming up in a picture with "Epic fail!" at the bottom.

Billy worked hard to promote an image of himself as an intelligent and able person. Most of the time he was successful as he was bright, articulate and put in extra effort to achieve an acceptable performance standard. When his inadequacies were exposed however, for example when he left his bag at the bus stop yet again, there was a sense of frustration and disappointment that he was unable to organise himself and his equipment like his peers.

Doubts about their ability to perform to an acceptable standard affected participants' motivation to engage or persist with activities; this was an increasing issue as tasks and contexts became more complex and the gap between participants' perceived competence and task expectations increased over time. Callum and David felt that they lacked the required level of precision in cutting, measuring and manipulation for 'design and technology' at secondary school. They were unable to complete a project within the required timescales and the poor outcome of their efforts reinforced their sense of inadequacy. Callum's expectation and experience of failure caused him to disengage emotionally from practical lessons:

Callum: I've never actually finished a project before.

Interviewer: How does that make you feel?

Callum: Well (*sighs*). I don't like it so I don't really want to finish it really, but a bit upset that I haven't achieved it.

While Callum withdrew emotionally from technology lessons, David withdrew physically:

Interviewer: Do you manage to finish your projects?

David: Yeah, but they look terrible. Sometimes they look terrible. I mean, I've got six weeks (*to complete the project*) but I'm three weeks down on one of the projects, so I just don't go, stay in the toilets.

David and Callum's inability to produce an acceptable product within the required timescale reinforced their lack of competence. By avoiding lessons however, David was able to attribute his poor performance to a lack of effort rather than lack of ability, thus saving face with peers who might be persuaded that he could have achieved more if he'd wanted to. However, withdrawing from technology lessons limited opportunities for David to practice and master the ability to handle

and control tools and equipment, skills which could transfer to other situations and might be useful for the future.

Concern about how others perceived their competence affected participants' willingness and motivation to engage in activities which might expose their coordination difficulties. George for example, thought carefully about the activities he chose to participate in to avoid embarrassment:

George: I'm quite a person who doesn't wanna go to things sometimes... not want to do certain stuff because I think I'll be the worst there or something like that.

George's sense of competence was affected by the anticipated or actual reactions of others; his concern perhaps reflects previous experience of humiliation and ridicule. David was also concerned about how others might perceive him and was reluctant to eat in public because his inability to handle cutlery effectively made him feel stupid:

David: I can't use a knife and fork neither. The food either goes on the floor or I make myself look like an idiot.

David was embarrassed when his coordination difficulties were publically exposed. Participants' accounts indicate a vicious cycle of failure experiences, a sense of perceived inadequacy, and participants withdrawing from activities that they felt were beyond their capability leading to fewer opportunities for them to develop mastery. Participants were therefore likely to experience further failures because of poor skill development. Furthermore as activities became more challenging when task demands increased and environments became more complex as participants matured, this added to the challenge and in some cases made participants feel even less able.

Anger and frustration

Feelings of frustration were shared by all participants and were heightened when activities didn't go as they hoped because of real or perceived inadequacies and when they were prevented from achieving a goal or an acceptable standard of performance by factors beyond their control. Some participants externalised their frustration, while others internalized their feelings and became withdrawn.

Participants shared a sense of frustration when coordination difficulties prevented them from achieving a standard of performance that others managed easily:

George: It's frustrating when everyone else can do it like straight away, then when I try and draw a cube or something it turns out really weird and stuff.

George's dissatisfaction was heightened when he performed poorly in comparison to his peers despite trying hard, and when teachers didn't recognise the effort he'd put in. David was exasperated by his teacher's instruction that he should work harder when he had already tried his best:

David: They just say 'Try and make it neater'. How can I try and get it neater?

Participants were frustrated not only by their inability to attain the standard of performance that they hoped to achieved, but by what they regarded as the unnecessary complications that school routines and structures imposed on them. David felt disadvantaged by the requirement to bring a different PE kit on alternate weeks and was irritated that his poor memory and organisational skills made him more likely to get into trouble:

David: It's like getting my kit right and that. When I've got, one week you've got to wear white kit and then a black kit. Why don't they just wear one normal kit?

David tried hard to contain his frustration to avoid getting into trouble at school. On occasion however, participants were unable to contain their emotions and a seemingly trivial event could tip them rapidly from a state of 'coping' to 'not coping'. A build-up of frustration, pressure and anxiety throughout the day caused Ian to explode and vent his feelings physically:

Ian: This one time when I had, I got a pencil and I threw it at a fan and it didn't have the cover on. Then I got really, really angry. I don't know why, I just did and I kept throwing the pencil at the fan. Eventually a teacher walked in as I threw it, the pencil snapped and it hit someone in the head and they had a complete go at me and I kept talking to them back. I kept arguing, for some reason, and then I got in a lot of trouble for that.

Ian reached a point where he was unable to contain his anger and frustration and took his emotions out on a classroom fan. This had both behavioural and social repercussions however as Ian received a detention and peers realised that they could goad him to provoke a reaction. David suffered similar negative consequences when he externalized his anger and frustration by 'acting out' physically. Ian and David were caught up in a negative cycle of building frustration and angry outbursts, the consequences of which affected their social relationships, confidence and self-esteem.

Ian and David expressed their emotions physically; by contrast Harry internalised his feelings of anger and frustration. He became angry with himself when his behaviour affected people he was close to, for example if he had squeezed a friend too tightly or knocked someone accidentally during

a game of football. Harry was overwhelmed by his feelings of disappointment in himself and responded by shutting down emotionally.

Stressed and anxious

Participants identified a number of factors that caused them stress and anxiety. Most felt under pressure to achieve academically and worked hard to present themselves as capable and able to cope. Some participants felt constantly on edge, worrying about things that might happen because of their poor organisation and coordination skills. Feelings of stress and anxiety were heightened in certain contexts; however, participants generally felt more relaxed at home where there was less pressure to conform or perform.

The consequences of constant pressure to perform at school were significant for some participants who felt on a treadmill of continual assessment between the ages of 13-15 years. Billy had very high expectations of his academic performance and put pressure on himself to achieve top grades:

Billy: The problem is I've got this image inside of me of the person I would like to be, but that person's pretty hard to get to. He's perfect in every way so there's always pressure.

Billy was very critical of his own performance and was frustrated and anxious about the difference between his ideal self and his actual self. He worked extremely hard to compensate for his difficulties, for example by spending much longer on his homework than his peers and felt guilty when he spent time away from his studies to watch TV or play table tennis with his friends. At 13 years of age Billy experienced psychosomatic symptoms of stress and anxiety. However taking time off school added to the pressure as he had to catch up on missed lessons and was teased because of his frequent absences. Ian also found the pressure of assessment and continuous revision difficult to cope with:

Ian: It's just the amount of work and it's just that constant strict regime you're forced into, to keep going and keep working. I just don't deal with it very well.

Ian was anxious to portray himself as someone who was able to cope academically. He avoided asking or answering questions in class in case he got them wrong and was reluctant to ask teachers for help, but this meant that he was often unsure about what he was supposed to be doing. Furthermore, being told off for not concentrating and achieving poor grades for completing work incorrectly affected Ian's motivation to persist in class. George also worked hard to appear capable so a teacher's public comment about his poor handwriting affected his confidence:

George: In one of my lessons, like if someone said something to me, like a teacher, about handwriting or something I would just be less confident for the rest of the day.

Negative feedback from peers and teachers had a cumulative negative impact on participants' self-esteem and confidence and affected their motivation to put themselves forward in class, thus limiting opportunities for them to learn and develop.

Many participants felt anxious because of things that might happen. They anticipated scenarios in which their lack of motor coordination and disorganisation would cause them embarrassment, injury or get them into trouble. George referred to this anticipatory anxiety as the "*What if?*" thing that went on in his mind. Billy anticipated getting into trouble at school because of his poor organisational skills:

Billy: (*I get stressed*) when I thought I am in trouble or I'm going to get in trouble, say I forget my books or I haven't done my homework, then I would stress about it.

Billy's anxiety was heightened by his constant alertness to the possibility of forgetting something and potential consequences such as being told off by a teacher, being marked down or missing an appointment. Billy worked hard to avoid getting into trouble or letting himself down at school by putting in extra time and effort to be prepared.

Participants' anxiety levels were also affected by context; several identified design and technology lessons as particularly stressful as they anticipated injuring themselves because of their poor motor coordination:

David: I don't feel comfortable using like the main woodworking materials at school, don't like the equipment we use because it's sharp and I'm just scared to use it.

Participants' anxiety about handling sharp or hot tools was often based on previous experience and affected their willingness to try new activities; in the case of kitchen skills, this anxiety inhibited the development of their independence skills. In contrast to school however, there was less pressure to perform or conform at home:

Ian: You work at home as well, but it's nowhere near as pressured if it was at school to get it right. And of course at school you've got everyone else around you so you've still gotta maintain an impression whereas at home you can just chill and do it at your own pace, not be pressured, not be (*sigh*) put under any restrictions either.

Ian felt more relaxed in the safety and predictability of the home environment where he felt in control and was less worried about drawing attention to himself or getting into trouble for not performing to the required standard.

Coping

Participants identified a range of strategies and activities that helped them to manage their emotions at home and at school. Several reported that physical activities such as playing football or walking the dog helped to diffuse tension when they were feeling stressed, anxious or angry. Non-physical activities such as reading, drama, poetry and music also helped them relax. Losing himself in creative activities was particularly important for Billy, enabling him to escape from pressures associated with his coordination difficulties and his strive for perfection:

Billy: Like poetry, like reading a book, you can pour yourself into it, you know? Because that's something that's yours, that piece of music is yours, that book is your story to read a different way and with some poetry you're, it's only you that's reading that and having that thought, so it automatically, that's yours and that's something you can really pour yourself into without anybody else thinking about it or doing it in any other way.

Billy's insight into the value of creative activities was surprisingly mature. He was able to immerse himself completely in these activities because there was a perfect match between them and his abilities. Furthermore there was no pressure to perform to a particular standard offering him respite from his own high performance expectations and the everyday pressure that he faced because of his coordination difficulties. Billy also identified the non-competitive nature of Scouts as a pleasurable pro-social activity where he could relax and be himself:

Billy: It's not set up to be overly-competitive, everyone gets on...when you do mess up or you bang into someone or spill the water out of the cup or something then it's alright. When you do make mistakes, someone's laughing, you do laugh, people laugh with you rather than at you.

Participating in non-competitive social activities was particularly important for participants who lacked confidence in their physical abilities, providing them with opportunities for positive social interaction and boosting their confidence and self-esteem.

Some participants had received professional help for their emotional well-being, including counselling and support from child and adolescent mental health services. It was interesting to note that Billy's ability to cope with stress and anxiety evolved over the course of the study. At 13 years of age he described himself as stressed and anxious nearly all the time. To help manage his worries he

had been allocated a school mentor, but Billy was concerned that the informal arrangements offered to support his emotional well-being actually heightened his sense of difference and counteracted any benefits to his stress and anxiety. He felt there should be more formal support systems in place:

Billy (aged 13): If there was someone that was especially there to help with stress and people knew about it, maybe that they had their own room and it was signposted for, that I wasn't on my own going there, then I think that would make it a lot easier.

Billy felt isolated and “*weird*” not only because he felt stressed and anxious, but because the support strategies implemented by school were inappropriate and difficult to access. By the time Billy was 15 however, he was more confident in his ability to cope:

Billy (aged 15): I've learned how to deal with it and put it in perspective. I'd worry about ridiculously small things and so I've tried to, try to sort that out really.

Billy was less concerned about things that might happen because experience had shown him that problems he anticipated didn't always occur. He also felt less anxious about exams as he was interested in the subjects and was familiar with the exam process. Indeed, Billy felt more prepared for his exams than some of his peers because of the extra practice and revision he had put in throughout his school career. George also felt less anxious as he got older because he'd had more experience of successfully coping:

George: At one time I felt like I couldn't like do anything and achieve anything, and I'd say it does get more manageable and better as you get older.

Likewise Freya's determination and resilience was enhanced by her experience of mastering activities that others thought she would not achieve:

Freya: They said to my mum that I wouldn't be able to do things like, when I'm older and stuff, but I can do them so it's like “You said that I couldn't do it, but I can!”

Freya's determination and motivation to succeed was actually enhanced by being told that she might not be able to achieve. Successful experience of mastering activities through practice and with support therefore heightened Freya's optimism about her ability to perform activities that mattered to her.

Summary of master theme 3

The theme “*Don't get me wrong, I'm an intelligent person but I can't even write*” highlights an association between DCD/dyspraxia and anxiety, depressive symptoms and behavioural disorders in

teenagers. The findings broaden understanding of the emotional impact of DCD/dyspraxia by providing qualitative information about the different sources of stress, anxiety, anger and frustration from the young person's perspective. Rather than always assuming a negative emotional impact, however, the findings indicate that some develop coping strategies and support systems that promote positive self-esteem. This knowledge will help parents and professionals to better understand and support young people with DCD/dyspraxia to develop a positive sense of self-worth and improved life satisfaction.

Master theme 4: Right help, right time

The theme 'Right help, right time' focuses on teenagers' perceptions of the support they needed or were offered at school. Participants perceived that teachers' limited awareness and understanding of their diagnosis limited their access to strategies that would enable their school performance. Many participants were frustrated that the support available was not appropriate for their needs and felt disadvantaged by school systems that made life more difficult for people with DCD/dyspraxia. Some participants regarded alternative equipment as a useful compensation for their motor difficulties. However, its availability and accessibility affected its acceptability and effectiveness. Participants who were involved in identifying their own support needs felt empowered and more positive about managing their difficulties as they progressed through the school system. This master theme includes the following secondary themes:

- *"They don't understand me and my ways"*
- Disadvantaged by the system
- *"I suppose it's better than being in the hall and struggling with my handwriting"*
- Involved and empowered

The experience of school for teenagers with DCD/dyspraxia was of particular interest and concern to members of the Reference Group. I have therefore chosen this theme to highlight how insights offered by the Reference Group enhanced and deepened the analysis.

"They don't understand me and my ways"

Participants felt unsupported by teachers who were ignorant of their diagnosis and felt let down and anxious when their academic potential was not recognised. A teacher's uninformed comments about George's performance reinforced his sense of inadequacy, affecting his confidence and belief in his ability to be successful:

George: When teachers don't know about it they comment on handwriting or like cutting out, because normally if we're doing cutting out I'm always the last to finish or *(they'll say)* "this bit looks rubbish".

Participants thought it unfair that they were singled out and criticised by teachers who were unaware of their coordination difficulties; this was a particular problem when participants were taught by teachers whom they saw only occasionally. George was frustrated and demoralised by a teacher who implied that he had not tried hard enough:

George: The teacher's just totally ignorant of dyspraxia, totally.

Interviewer: What makes you say that?

George: One of my books she wrote ‘Good grief, how can you revise from this sort of writing?’ and ‘Why are your words dropping off the line?’ and stuff like that.

Interviewer: Right, and how did you feel when you heard that?

George: I was a bit, I was annoyed, I was really annoyed at the start and then after a while I was just like yeah, I don’t really, at the end of the day you’re just a teacher. I don’t really, I know like my writing’s not amazing and I know not everyone can read it, but it is annoying when teachers do say stuff like that.

George was upset that his teacher didn’t know why his writing was illegible and was annoyed that his poor performance was attributed to a lack of effort or carelessness when he had actually tried very hard to achieve an acceptable, if not ideal, standard of performance. George was humiliated by his teacher’s comments and lost respect for her because of her uninformed opinion and he was therefore less motivated to apply himself in her lessons because he felt his efforts would not be rewarded. Participants recognised that their teachers’ comments, actions or inactions were usually the result of ignorance rather than a desire to make things deliberately difficult for them, but felt let down when they did not receive the support and understanding that they needed:

George: I mean, obviously they have a passion for it (*teaching*), so they’re gonna try and help, but I think there’s not, with all due respect to them, there is not enough understanding in place to be able to combat like, what to do with it.

David: What I do think is that they should like, they should like go on a teacher training day ... they should know what half the stuff is and what they need to help like. Just like, say if they go on a course just to explain about special needs then maybe that would help just that little bit.

David’s assertion that even a “*little bit*” of training would be an improvement demonstrates how misunderstood and unsupported he felt: it was a source of anger and frustration that some teachers wouldn’t allow him to use the strategies that he knew would make a difference. A concern noted by the Reference Group was that teachers who didn’t recognise or understand DCD/dyspraxia were less likely to accept or encourage different ways of working. This was stressful for students who were therefore unable to access or demonstrate their learning. When first interviewed David said that “*half the teachers don’t let me use it (laptop)*”, but he lacked the confidence to explain how the laptop helped him and was unwilling to draw attention to himself by raising the issue in front of peers. While participants thought that raising awareness of special needs and DCD/dyspraxia was

important, George's view was that training sessions would have little impact unless teachers were given the skills and resources to apply this knowledge practically:

George: Like you can have all the information, but if you don't know how to put that into practice and make it better it's not gonna be a good thing.

George felt that teachers needed to develop a practical understanding of DCD/dyspraxia and not just a theoretical one. Furthermore, he believed that teachers had a professional responsibility to know about dyspraxia and felt let down by those who didn't seek to understand:

George: I know this sounds kind of bad but I kind of think they should kind of know about it, because they're there to know, they should know, because if someone had, I don't know, if someone was disabled or something they'd know straightaway. Just because you can't see it, it doesn't mean that you shouldn't like know about it. It's just annoying.

George felt disadvantaged because his difficulties were 'hidden' and observed that pupils with more obvious needs received better support. Falling under his teachers' radar was however both a blessing and a curse: while George was grateful that his difficulties were not severe and obvious, he was also upset and annoyed when his difficulties were exposed and then dismissed or trivialised by teachers whom he felt had a professional duty to help him.

Participants felt strongly that there was a need for teachers to have a greater awareness and understanding of DCD/dyspraxia. However they also felt that teachers needed to consider each person's unique profile of strengths and difficulties as strategies that worked for one person might not work for another. The Reference Group agreed that no two individuals with DCD/dyspraxia were the same, highlighting that 'general' strategies to support students with DCD/dyspraxia were not always appropriate and could have unintended consequences for an individual. David was frustrated that some teachers were aware of his diagnosis but didn't have a good understanding of "*me and my ways*", as illustrated by his description of a teacher's efforts to help by positioning him towards the front of the class:

David: My catering teacher, she understands but she moved me to the front like all the time. She, because like when we sit down in alphabetical order and I'm (*surname beginning with W*) so I'm last, but I'm right at the front.

Interviewer: Right, so do you think that's good that she moved you to the front?

David: Well, it helps me out but at the end of the day it makes me a bit sad that the plan is all out of order. But at least she knows what I've got.

David's teacher made prejudgements about his support needs, based on his diagnosis. However, adjusting the seating plan was contrary to David's need for predictability and he was anxious when the change in arrangements invited questions from peers which made him feel "*quite peed off*". By contrast David felt that his individual needs were understood by his woodwork teacher following a visit from his Mum:

David: The technology teacher's like, since my mum has gone in, has sort of been really effective now.

Interviewer: OK, so he understands it a bit more?

David: Yeah, and I think he's probably done some research or something 'cos like now he's been told he's like got his arse out and it's started working, helped me.

His Mum's intervention had significantly improved David's experience of woodwork, a subject area that had previously been an area of great stress, frustration and disappointment. The Reference Group observed that adopting an individualised rather than a generic approach to supporting students with DCD/dyspraxia was more likely to have a positive impact on teenagers' performance and participation than generic approaches that did not take into account the interaction between an individual's characteristics (including their psychological, physiological and cognitive abilities), school tasks and the context in which the activities took place.

Participants were angry and disappointed when teachers judged them as less intelligent because of the poor presentation of their work. David's poor handwriting masked his abilities and he was frustrated when placed in inappropriate sets with lower performance expectations:

David: Because I ain't got neat handwriting like, I'm not getting pushed enough, I'm in bottom sets for most things and like, not bottom sets but not the sets I should be in.

Interviewer: So you think that's because your writing is not so good?

David: They can't read my writing, no. And I'm not getting any marks on my tests.

David was aggrieved that his work was marked down because it was poorly presented and was unenthusiastic about lessons where he wasn't being stretched academically. Callum also thought his teachers were unaware of his academic ability because he prioritized presentation over quantity:

Callum: I have to make it (my writing) short so that I can finish it in time if I know that, like if they say '5 minutes left' then I have to like take a bit away. So they (teachers) don't say anything because they haven't really noticed.

Callum worked hard to ensure his writing looked finished, but received lower grades because his work was marked according to what he had written not what he was capable of producing. Receiving low grades added to his low self-esteem. Callum's sense of invisibility was further reinforced by teachers who did not notice when he was assaulted in the classroom, commenting that *"they could have been more alert I think"*. Callum's sense of insignificance and worthlessness was heightened because his academic potential and social vulnerabilities were not recognised by teachers whose role, he felt, was to protect and support him.

Feeling misunderstood, invisible and unsupported had a significant impact on Harry's emotional well-being. When asked by a teacher to account for an incident at school Harry felt that his anxiety was misinterpreted as dishonest behaviour because the teacher did not recognise or understand his condition:

Harry: The head teacher said 'You're lying, you're lying because people who fiddle are lying'. But that's the absolute opposite. I fiddle when I'm telling the truth. I can't fiddle when I'm lying, if you get what I mean?

Harry felt rejected and unsupported by staff members who did not understand or believe him and who, as a result, did not protect him from bullying and intimidation by peers. An accumulation of negative experiences resulted in Harry having what he described as *"a nervous breakdown"* after which he was removed from school by his parents until an understanding and supportive specialist placement was found for him. Being misunderstood therefore had a devastating impact on Harry's emotional and academic well-being.

Disadvantaged by the system

Many participants felt disadvantaged by school systems that prioritised the needs of students with cognitive learning difficulties and those for whom English was a second language. Participants felt ignored because their learning difference was different to that of other students. George for example, felt out of place when invited to attend the learning support unit with students who had very different learning needs to his own:

George: The first time I went in there like they were doing stuff which I was like, obviously I know they've got kids with special needs and they were doing stuff with this calculator and stuff, learning to count to ten and stuff. I mean I don't want to sound rude but I can do that, I don't need help with that.

George accepted that he had special needs, but recognised that help was targeted towards students with learning difficulties whereas he was academically able. His view was shared by other

participants who felt that the help offered was inappropriate, commenting that being withdrawn from class for special lessons was “*pointless*” and “*a waste of time*” (Billy) or “*boring*” (David). Participants opted out because they did not feel that the support offered would improve their school performance:

George: Everyone got the same in there so I don’t think they really differentiated between like dyslexia, dyspraxia or autism, whatever it may be. I think they just sort of gave everyone the same sort of support... and that wasn’t what I needed.

The Reference Group observed that participants felt let down by systems that were supposed to support students with additional needs; furthermore the lack of understanding of DCD/dyspraxia by specialist teachers heightened participants’ sense of isolation and difference. This was particularly the case for Callum who felt disadvantaged by a ‘one size fits all’ approach. Whilst he needed help with practical activities such as woodwork, help was not offered in these subjects as these were areas that students with cognitive learning difficulties typically managed easily:

Interviewer: Are there any other people at school that get extra help or support?

Callum: Yeah (*pause*)

Interviewer: And do you think that any of the help they get would be useful for you as well?

Callum: Yeah but, because they are all good at technology I think, so they don’t really need help there.

The Reference Group noted that Callum felt lost within the school system and invisible because his support needs were not noticed or prioritised. Ian was likewise frustrated that help was available for certain students, but not for him. He had concluded that he did not “*qualify*” for additional time in exams because an assessment had focused on his academic ability rather than his ability to produce legible written work at speed:

Ian: They gave me the thing to fill out and they kind of judge it on how smart you are, not necessarily if it’s, how long it would take you to answer it. In some exams the extra time would have benefitted, whereas just because you filled out the form and got it all right you’re not eligible for the extra time.

Ian felt his teachers lacked the tools, skills and experience to adequately assess his coordination and organisational difficulties and that key areas of difficulty for him were missed. He felt disadvantaged because he was “*smart*” and was confused and frustrated that as a result he didn’t qualify for extra

time in exams and could not therefore demonstrate his potential. By contrast, Billy was offered the ‘standard’ support for students with additional needs which was extra time in exams, but felt that had he been offered help with essay planning and time management skills he might not have needed extra time at all:

Billy: I could finish most of my exams in plenty of time, but because I write so much I do struggle. I mean, if I kept it focused to the question I reckon I could, I could finish them with it, without the extra time.

Participants felt disadvantaged by school systems that did not acknowledge or prioritise the support needs of students with DCD/dyspraxia. Furthermore, the feeling that they were different from students with other learning needs contributed to their sense of isolation and confusion.

“I suppose it’s better than being in the hall and struggling with my handwriting”

Having a diagnosis enabled some participants to access specialist equipment and support at school; the acceptability and effectiveness of these supports however depended on participants’ perceptions of the psychosocial impact of appearing different to their peers, whether equipment was accessible and provided without fuss, and how much difference it made to their performance and participation. Participants felt strongly that effective supports and equipment were not ‘benefits’ but compensations for their coordination and organisational difficulties.

Participants evaluated the use of alternative equipment and strategies from both a psychosocial and a functional perspective. As described previously negative social consequences, such as unwanted peer attention meant some participants rejected equipment or support that might have improved their school performance. Billy was too proud to accept specialist support because he thought this might be perceived as an excuse for poor performance and his test scores would therefore be regarded as less valid:

Billy: There’s quite a lot of support for people that are struggling in tests, but I think a lot of the time you are almost embarrassed to take that support as if it’s, as if you are just making an excuse for not doing particularly well.

George evaluated the social cost and benefits of having adult one-to-one support in lessons and was relieved to conclude that this would not benefit his learning. By contrast, Adam was happy to have adult support because it helped him to understand what was expected of him. It was important for Adam’s self-esteem however to retain his independence by recording his own answers:

Adam: (*I have*) a support assistant to help me. They just help me with my work, yeah, and if I get stuck on something they'll tell me, they'll help me with it... They don't write it for me. They help me with the questions and I'll write it. I'll get the answers down.

By contrast Freya and David did not want an individually assigned support assistant in class because they perceived the social cost as greater than any benefit to their academic performance. Both were however grateful to have access to a general teaching assistant who was available to support the learning of all students:

Freya: There's a TA (*teaching assistant*) that goes in most of my classes but she's not specifically helping me, she's just there to help everyone sort of thing. But if I miss something they always write it all down so then if somebody misses something they just go and give them the book they've written down, so then you just copy it out of their book.

Freya didn't need help all the time but was relieved to be able to tap into support as and when she needed it. Likewise, David also accepted "*a little bit of help*" from a general classroom assistant who helped him process information and instructions because there was no stigma attached to accessing support that was available to all students.

It was particularly important to participants that accommodations for their coordination and organisational difficulties were made without fuss. Members of the Reference Group observed that teenagers' perception of the effectiveness of alternative equipment and support in reducing barriers to learning was significantly affected by its accessibility and availability. Freya and David were willing to use a writing slope in class even though it drew attention to their difficulties, because experience proved that this improved their handwriting and because writing slopes were made available in the lessons where they needed them most. Billy however was frustrated and embarrassed when arrangements to accommodate his extra time in exams weren't properly planned:

Billy: History exam I was the only person with extra time and because they messed up the exam timetable I had to move rooms to finish it off 'cos another exam was starting. Yeah (*laughs*), so that was annoying.

Eden was also annoyed when he had to move seats to sit next to a plug socket or search for an assistant because his laptop was not charged up. Even though he found it easier to type than to write, Eden's description of his laptop as "*rubbish*" on a number of occasions illustrates his frustration when it wasn't available for use. The Reference Group reflected that failure to address technical issues in a timely manner and poor consideration of practical arrangements were

significant factors affecting whether or not laptops effectively supported teenagers' school performance.

Coordination difficulties presented some unexpected challenges and occasionally prevented the effectiveness of supports and accommodations that might have been beneficial; Eden for example, struggled to handle the laptop case and strap that had been provided:

Eden: It's got like a weird neck thing which goes like that, but I can't do it properly so I just dangle it round my neck and put my arm through it, but it doesn't really work...it puts lots of strain on my neck, like around here. Like in Year 7 I had a massive mark around it one day.

The laptop was therefore more of a hindrance than a help for Eden's learning at times. By contrast, George was positive about using a laptop despite it drawing unwanted attention from peers, as it reduced his anxiety about the presentation of his work and allowed him to express himself more freely on paper; he described using a laptop in English as being "*just like perfect*". Likewise, David was relieved when allowed to use a laptop in exams:

David: It's a bit of a relief. I'd usually be like stressing over it and that, losing sleep but this year I've just been able to focus and that.

Interviewer: Why do you think that is?

David: Because of like, with the handwriting I'd be worried about the neatness and that, but now that really isn't a problem.

David was relieved because he was able to produce work that was legible and was a true representation of his academic abilities. Harry and David had both been offered a scribe to record work for them in lessons and exams. However, while Harry thought this was a good accommodation for his handwriting difficulties, it was not a simple solution as David explained:

David: It was kind of hard because I'd like want them to write faster than what I'm saying 'cos like when you're saying it you end up going slow, but it's good, it goes good.

Even though it was difficult to work effectively with a scribe David felt it was worth the effort because of the improvement to his grades. He felt "*good*" that he was able to get down what he wanted to say on paper. Furthermore, having a scribe reduced his anxiety about being marked down because of poor presentation. By contrast, Callum did not receive the help and support that he needed in woodwork lessons, even though there was an assistant in the classroom. Callum saw an

opportunity for the technician to teach him how to handle equipment and use tools safely, but lacked confidence to ask for assistance:

Callum: There is another technician who helps people, but well he didn't really help but he makes all the wood. Maybe he could help more, like because he has helped me a little bit previously.

Interviewer: How could he help you do you think?

Callum: Maybe show me how to like use the saw, cos they haven't really done that, like how to use it properly yet.

George was clear that the support he received, including extra time in exams were not privileges, but helped him to perform on an equal footing with his peers. He would however willingly give up the supports that others perceived as advantages, if he didn't need them in the first place:

George: I'd much rather not have the benefit and not have dyspraxia, than have the benefits and have dyspraxia.

On balance, participants were prepared to accept the frustrations and social cost of being different at school if this meant they were able to demonstrate their academic competence, as demonstrated by David's thoughts about being separated from his peers for exams:

Interviewer: So how do you feel about being different to everybody?

David: Ah that's, yeah it's not, it's not good but I suppose it's better than being in the hall and struggling with my handwriting.

Involved and empowered

At 13 years of age many participants felt ignored and disempowered by teachers who did not understand them, and disadvantaged by school systems that made them feel inadequate and stupid. David was resentful of teachers who didn't listen to his views and take him seriously:

David (age 13): She just don't listen to me. She thinks she knows what's best for me, and I know what's best for myself and no-one accepts that, cos I'm just a kid.

Interviewer: OK. And she comes to see you how often?

David: It was just a one-off, just to give the school equipment.

Interviewer: She came once?

David: Yeah, it was after Christmas.

Interviewer: And did she talk to you?

David: No, she just talked to (*class teacher*). She gave me this sticky thing that I put my woodwork on like, and everyone will look at me cos it's actually like this thing. And she gave me like these scissors and it was just like she knew what's best.

David felt the teacher hadn't taken the time to get to know him properly and had suggested equipment based on its theoretical usefulness without considering its social impact. Failing to take into consideration David's views left him feeling disempowered and resentful, resulting in him rejecting equipment that may have been of benefit. David felt his opinions were dismissed because of his age and was frustrated that his personal experience of living with dyspraxia wasn't valued. As participants progressed through the school system however, their self-awareness and sense of agency was enhanced by teachers who acknowledged their strengths and difficulties and who involved them in identifying strategies and accommodations. David was positive about his active involvement in regular reviews of his individual education plan (IEP) at school at 15 years of age:

David (age 15): We have like an IEP (*meeting*) at every half term and we discuss what we can do to improve and things like that.

Interviewer: OK, and how do you feel those meetings go?

David: Yeah, they go well. They're like every half term so and then there's an improvement, so yeah, it's getting better.

David attributed the improvement in his school experience and performance to these meetings because they enabled him to explain the strategies that worked and because he felt listened to. His sense of involvement is clearly illustrated by his use of the word "we" when describing the process. David's sense of agency and empowerment was also enhanced by his involvement in writing his own personal profile to explain to teachers his strengths, difficulties and support needs. Other participants also felt an increasing sense of empowerment as they progressed through the school system, perceiving greater flexibility about how they worked and learned:

Billy: The teachers generally treat you as adults rather than children so in that sense you've got a bit more sort of freedom in how you work and how you make decisions about how you work, so I like it in that sense.

Billy felt empowered in an environment where he was expected to have a greater awareness of his strengths and learning needs. The importance and value of self-knowledge was reinforced for Ian when he was asked to indicate whether he had any additional needs on a college application form. During the interview he was asked directly how his diagnosis affected him:

Ian: On the application form they had a box for dyspraxia and I ticked that and they asked me (*about it*) in the interview, they can re-test me for extra time as well, and whether I need a learning support assistant which they would, if I chose to go to (*college*) then they would offer me should I need it.

Ian's animation when describing this experience illustrated his excitement that his prospective tutors would understand his difficulties and that support systems were already in place for students like him. He felt optimistic that his needs would be understood and that he would be involved in identifying strategies to enable him to be successful in his studies. Likewise David was reassured when told by his mentor that dyspraxia was recognised at university was pleased to hear that all students (not just those with additional needs) were encouraged to use laptops for assignments and to take notes in lectures so that he would be the same as everyone else. The Reference Group highlighted how enabling teenagers with DCD/dyspraxia to identify and use the strategies and supports that enable their performance would increase confidence in their ability to solve problems, an important skill for the future.

Summary of master theme 4

The findings described in this section offer a unique insight into teenagers' perspectives on the support available and provided to them at school. Participants felt disadvantaged by teachers' lack of awareness of DCD/dyspraxia and by the unanticipated consequences of organisational solutions to their difficulties when their individual needs and preferences were not considered. They were frustrated by school systems that prioritized the needs of other students over those with DCD/dyspraxia. While participants recognised the benefit of using alternative equipment and having access to support for their learning needs, the acceptability and effectiveness of these solutions was affected by the way in which help was offered and by its accessibility and availability. The findings also suggest that there was a change in participants' attitude towards 'doing things differently' at school over time. Participants who felt involved and empowered were more positive about their ability to manage their difficulties as they grew older.

Master theme 5: Making sense of the diagnosis

This final master theme explores participants' relationship with DCD/dyspraxia and their attempts to make sense of the diagnosis. Learning about and understanding DCD/dyspraxia was experienced by participants as a process characterised by feelings of isolation, confusion and uncertainty. While some participants coped by disassociating themselves from the condition, others were relieved to know that there was an explanation for their difficulties. Participants' adjustment to and acceptance of their diagnosis was influenced by the impact of their difficulties on everyday life, by the environment and by others' understanding and acceptance of their differences. This master theme is divided into the following secondary themes:

- *"I knew I was different from most other people"*
- Being diagnosed
- *"I didn't really know what it was"*
- *"I can't do much about it, that's just who I am."*
- Disclosure

As all participants referred to their diagnosis as 'dyspraxia', this term is used in preference to DCD throughout this section.

"I knew I was different from most other people"

For some participants there was a period of feeling that something was different about them before they learned about their diagnosis; for these participants dyspraxia was experienced as an 'absent presence' during their younger years. Like other participants, Freya had a tacit understanding that she was *"just a little bit different"* to her peers without knowing why. These feelings of unexplained difference increased as participants' awareness of their difficulties became more obvious over time. George felt similar to his peers at primary school, but became aware of the poor presentation of his work compared to his peers as he got older:

George: Everyone in primary school has got like really bad handwriting and stuff and I didn't really notice it, but then I didn't really know what it was 'cause you're oblivious to sort of things when you're young, but I think as I'm getting older I'm realising more how it's gonna affect me.

Billy's experience was similar:

Billy (aged 13): I knew I was different from most other people, but I didn't really notice, I didn't at that point know what dyspraxia meant and I'm still not sure.

The sense of knowing but not knowing that something was different was reinforced by participants' experience of receiving specialist help when younger. It was only with hindsight that they realised interventions were provided to address symptoms or issues associated with dyspraxia:

George: I think before I was going to the (*child development*) centre and then like, but they'd never actually said I was dyspraxic.

Billy: For tests if I wanted to I could go in a different room... but they didn't label that as dyspraxia, they just labelled it that I couldn't concentrate very easily.

Billy and George understood that the help they received addressed difficulties such as poor balance, concentration and fine motor skills, but receiving interventions without understanding why reinforced their sense that there was an unspoken difference about them.

Being diagnosed

All participants had a formal diagnosis of dyspraxia, yet few were able to recall an occasion when their diagnosis was disclosed to them; most became aware that they had the diagnosis "*slowly*" (David) over a period time. Participants were vague about how long they had known they had dyspraxia and none was able to state confidently when they were diagnosed:

George: I'm not a hundred per cent sure, I think it was about, I think it was when I was in, I think it was when I was like 11 or 10, or around there.

David: I was diagnosed when I was about 6, something like that, really young because I, yeah, so I hadn't got any memories of that.

Participants' uncertainty was heightened because unlike other medical conditions which are confirmed by a blood test or another investigation, DCD/dyspraxia is a diagnosis of exclusion and typically involves formal testing by health professionals and a medical practitioner combined with information-gathered from parents and teachers over a period of time (EACD 2012). Participants seemed oblivious of the diagnostic process that they had presumably experienced and their diagnosis did not therefore represent a significant or 'life changing' event. Rather, participants became gradually aware that there might be a reason for their difficulties during their primary school years with many learning about their diagnosis from their parents or teachers. Only Ian recalled attending a specific diagnostic assessment:

Ian: We saw them about two times and on the second time they gave us a diagnosis.

Receiving a diagnosis at 13 years of age provided Ian and his parents with an explanation for his previous confusion, difficulties and failures. Rather than reinforcing his negative self-esteem and poor self-image, being diagnosed helped him and his parents in their search to understand and make sense of his difficulties. Likewise, George's suspicion that there might be a reason for his handwriting and coordination difficulties was confirmed by a reassessment at secondary school:

George: I remember doing like loads of tests and about like hand-eye coordination...I think after that they just said I was dyspraxic.

The re-assessment enabled George to access appropriate support and resources. For other participants however, delays in the disclosure of their diagnosis contributed to a sense of confusion and isolation. With hindsight, Billy realised that others (parents and teachers) knew about his diagnosis before him, an experience that was shared by members of the Reference Group. Callum sensed that his parents had avoided discussing his diagnosis with him:

Callum: My teacher told me about it. I think my parents already knew.

While Callum described his parents as "*kind*" and knowledgeable, he sensed that they were uncomfortable with the term dyspraxia and were reluctant to discuss it openly. This contributed to his feeling that dyspraxia was something to be ashamed of and may have been a factor in his disassociation from others with the condition, an issue that is explored later in this chapter.

Participants did not express strong feelings of anger or frustration that their diagnosis had been withheld from them. Instead there was an unspoken acceptance that their parents had avoided disclosing their diagnosis in order to protect their self-esteem and prevent them from developing a negative self-concept.

"I didn't really know what it was"

This secondary theme reveals participants' confusion and uncertainty about their diagnosis which continued even after they learned that they had dyspraxia. As discussed previously, not understanding their difficulties made participants feel stupid and affected their motivation to participate in certain activities or contexts, while negative feedback from peers, family members and professionals reinforced their sense of isolation and intensified feelings of self-doubt, shame and humiliation when things went wrong. Learning that they had dyspraxia did not provide immediate reassurance however, as the term had little meaning for them. Participants were puzzled by the variation in their skills and performance from day to day and for some, co-existing conditions and a lack of other young people with dyspraxia to whom they could compare themselves added to their anxiety and sense of isolation.

Having a diagnosis of dyspraxia did not immediately help participants to understand and make sense of their experiences because the term ‘dyspraxia’ had little meaning for them:

George: When I first found out and I was kind of, I thought it was like, I think I thought it was like dyslexia or something like that, then it’s quite a bit different.

Eden: My mum told me that I had dyspraxia. There’s one thing, like you can’t write very well, cos the teacher questioned if I might have dyspraxia. I thought “Oh what’s that?”

Callum: I kind of explained but it was kind of hard to explain since I don’t really know what it is.

George, Eden and Callum were unfamiliar with the term ‘dyspraxia’ and were confused about what it meant. In trying to understand the term George compared himself to people with dyslexia, but found this unhelpful as their experiences were different, reinforcing his sense of isolation. Eden’s reaction to the suggestion that he might have dyspraxia was one of curiosity and intrigue rather than anger or rejection, while for Callum having the label ‘dyspraxia’ did not provide him with the language to understand himself or explain his difficulties to others. His inability to provide a confident, succinct definition of dyspraxia added to his sense of inadequacy.

When asked to explain what they understood by the term ‘dyspraxia’ participants focused on physical aspects of the condition:

Adam: It means you’ve got problems somewhere in your body.

George: I’d just say like it’s a problem with hand-eye coordination, like foot-eye coordination, like you can find like subjects hard and stuff.

Harry: It means that you’ve got eye-hand coordination problems. It means that you can bump your head, your hand and your face a lot.

Ian: Fiddly things, it’s kind of a problem with coordination.

Participants found it easy to describe physical aspects of dyspraxia because they were the most tangible. However, as discussed previously, participants *experienced* dyspraxia as more than just a physical construct. There was therefore a discrepancy between how participants described dyspraxia and how they experienced it. Reference Group members suggested that participants’ inability to articulate how dyspraxia affected them contributed to the vicious cycle of misunderstanding and confusion surrounding the condition, and the ‘hidden’ nature of their disability.

Variability in their skills and performance also contributed to participants' confusion about what their diagnosis meant. While participants could manage some activities easily, other tasks were difficult, and while they were sometimes able to perform a task well, on other occasions they were not:

David: I can catch a football easy, but I can't catch a tennis ball. And I can't catch with one hand. Does that make sense?

Billy: I don't know what changes it, but every now and then I can do things, the next day hand-eye coordination all over the place.

David was clearly struggling to "*make sense*" of his confusing profile of strengths and difficulties, while Billy was puzzled by the variation in his performance from day to day. Their confusion was further compounded by comments from adults who might be considered 'experts' in dyspraxia:

Callum: The occupational therapist said 'Can you ride a bike?' and I said 'Yeah', 'cos he said people with dyspraxia can't really ride it as much.

Callum was confused because the therapist implied that people with dyspraxia find it hard to ride a bike, but this was something that he could manage. Callum questioned therefore whether he did indeed have dyspraxia or whether he was just stupid for not being able to perform tasks that his peers managed easily.

Some participants had co-existing diagnoses including ADHD, dyslexia and Asperger Syndrome and it was sometimes difficult for them to work out which 'symptoms' to attribute to which condition. Adam had a diagnosis of dyslexia and was unsure whether he still had this condition now that he also had a diagnosis of dyspraxia:

Adam: I think when I was little I did, did have it, dyslexia. Do I still got dyslexia now?

Harry regarded dyspraxia as part of his complex individual profile that included dyslexia, auditory processing disorder and dysgraphia and did not see the value in separating out each individual component. By contrast David was clear about which difficulties he attributed to autism and which to dyspraxia. The boundaries became less significant as he got older however, as he became more comfortable with and accepting of his own unique profile of strengths and difficulties.

For many participants the hidden nature of dyspraxia contributed to the sense of mystery about the condition and added to their feelings of anxiety and isolation. With the exception of Harry who

attended a special school for children with additional needs, participants only had a vague notion that they may know someone else who shared their diagnosis:

Callum: One of my mum's friends' son (*has got dyspraxia*) I think... I don't know a lot about him.

Freya: There's one other boy who's got it but he's really grumpy and moody all the time... I think he might have something else wrong with him as well.

Callum's uncertainty about whether or not the boy had dyspraxia reflects a previously discussed sense that dyspraxia was something that was skirted-around by his parents, rather than openly acknowledged and discussed. This secretiveness contributed to Callum's embarrassment and shame about having dyspraxia. While Freya didn't seem ashamed to have dyspraxia, she was embarrassed to share a diagnosis with someone she considered to be "*grumpy and moody*". She distanced herself from this individual by attributing his less favourable characteristics to something other than dyspraxia.

At thirteen years of age, most participants did not know anyone else with dyspraxia so were unable to compare their experiences or judge whether their difficulties were shared. Consequently they felt uniquely strange and isolated:

Billy (aged 13): I would like to know whether it's just me that's got these certain problems, or I'm not on my own really, because I'd rather not think of myself as weird but almost special sometimes and I think it would definitely be nice to know that I'm not the only one that does certain things.

Not knowing others who shared his diagnosis made Billy feel isolated and "*weird*". While David recognised similarities between himself and students with other disabilities, like Freya he was keen to avoid being inappropriately labelled and stigmatized:

David: Some of the kids have well, not dyspraxia, but they have, they've got (*problems with*) fine motor skills. It's not dyspraxia, like some kid's got cerebral palsy, he uses some of the same things that I use.

David recognised similarities between his difficulties and those experienced by the boy with cerebral palsy, but felt they weren't the same. Feeling 'similar but different' increased his sense of isolation as he didn't feel he belonged to the special needs group, but also felt different to his typically developing peers:

David: I'm a one-off, like I'm just someone, like there's a group (*of people with special needs*) and I'm just on the outside.

David felt on the periphery of both groups, but interestingly, his sense of uniqueness and isolation lessened over the course of the study. At 13 years of age he felt uniquely different because he didn't know anyone who shared his diagnosis, but by 15 years of age he was aware that there were other students with dyspraxia at his school. He was comforted by the knowledge that his experiences were shared by others:

David (aged 13): I'm the only one that has got dyspraxia in the school really.

David (aged 15): When I was in primary school and that, obviously I was the only one in the class to have things like dyspraxia but, but now I've got to senior school and I've gone to a school where a lot of people (*have dyspraxia*), like I know it's not, it's quite common.

David was relieved to know that he wasn't unique and his sense of being like others enhanced his social and emotional confidence. David was particularly excited to make contact with someone who shared his dual diagnoses of dyspraxia and Asperger Syndrome; his description of this connection as "*awesome*" illustrates the positive impact that knowing he was not unique had on his psychosocial well-being. By contrast, Ian at 15 years of age still could not find a group of people with whom he could identify and he made frequent comments reflecting his frustration at not being able to compare his experiences to others:

Ian: I'm not sure if other dyspraxics are like this as well, if they have a problem being quiet...I'm not sure if this is to do with the dyspraxia but it's just the way, as things come out it's kind of jumbled it, words aren't sometimes in the right order...I'm not sure again if this is dyspraxia but it kind of makes me act a bit more immature.

Ian was uncertain whether difficulties keeping quiet, communicating effectively or acting immaturely were shared by others with dyspraxia, or whether he was just stupid and incapable of doing things that others managed easily. Lack of a reference group was also a problem for Eden:

Eden: I don't know if that (*not being able to run far*) is because of the dyspraxia or because I am just plain lazy.

Eden wondered whether his lack of stamina was a feature of dyspraxia or just a lack of effort. Not understanding dyspraxia and its implications increased the likelihood of Eden and others internalizing negative comments made by others that they were lazy or hadn't tried hard enough, affecting their sense of efficacy and self-esteem.

For George the revelation that the actor Daniel Radcliff has dyspraxia was reassuring and inspiring:

George: It's obviously really good to know that despite the fact that he's dyspraxic, he's achieved so much and done so much and it's obviously good.

Although he didn't know Daniel Radcliffe personally, George was able to identify with him as a dyspraxic teenager and as someone who also had difficulties managing simple everyday tasks such as tying his own shoe laces. George was inspired by the knowledge that Daniel Radcliffe was successful in his personal and professional life despite his coordination difficulties.

"I can't do much about it, that's just who I am."

This secondary theme explores participants' relationship with dyspraxia and their acceptance of it as part of their identity. Understanding and accepting dyspraxia was a dynamic process influenced by participants' knowledge of their condition, the impact it had on their participation in daily life activities and by the reaction of others to their diagnosis.

Callum's relationship with dyspraxia was perhaps the most distant and uncomfortable of all participants in this study. Despite volunteering to participate and being willing to discuss problems with practical tasks and organisation, Callum talked about dyspraxia as if it was something experienced by other people:

Callum: They find it difficult to do things that normal people can do.

For Callum, accepting a diagnosis of dyspraxia would mean accepting that there was something different that would set him apart from "*normal people*". Dyspraxia was the elephant in the room: although Callum knew that he had dyspraxia he was unwilling to acknowledge it because doing so might have unforeseen social and emotional consequences. Callum's relationship with dyspraxia was one of suspicion and fear, heightened by a lack of knowledge and his sense of isolation which was perhaps reinforced by his parents' avoidance of the subject. While Callum's relationship with dyspraxia was one of denial, Ian acknowledged his diagnosis and was relieved to know there was something to which he could attribute his difficulties and experiences:

Ian: I felt like I, there was something, I knew that there was something to sort of blame for it.

Knowing that there was a reason for his difficulties reassured Ian that he wasn't stupid or hadn't tried hard enough. The diagnosis provided a legitimate explanation for his difficulties and enabled him to make sense of previous life experiences. Likewise, being able to attribute his motor, sensory and organisational difficulties to dyspraxia helped Harry by providing a counterbalance to the

negative feedback he had received from uninformed teachers who interpreted his behaviour as deceitful rather than something he could not control.

David's accounts indicated that his relationship with dyspraxia developed over the course of the study and was influenced by his knowledge of the condition and contact with others who shared similar experiences. At 13 years of age David was frightened of researching the condition because of what might be revealed, describing the websites his mum used for research as "*boring*" with "*too much information*". By 14 years of age however, he was actively using Facebook to carry out research and make contact with others who shared his condition. Furthermore he had the confidence to respond to queries, contributing his own experience of living with dyspraxia to help other teenagers and their parents:

David: If they're like asking questions like 'My teenage son does' I'd like put something up, if it's something I know about.

For David, having access to appropriate information about dyspraxia and being able to share his experience was an important part of the process of accepting and make sense of his diagnosis.

Participants did not see their problems as severe and didn't define themselves by their diagnosis; moreover, there was a strong sense that in most aspects of their life they felt just like any other "*normal*" (David) teenager. For George, dyspraxia was not a dominant feature of his identity as it didn't affect everything that he did, all of the time; indeed, there were many contexts, activities and times when he felt that dyspraxia did not affect his enjoyment or participation at all:

George: It's not a continuous problem.

Eden's experience was similar; he felt that dyspraxia "*doesn't really matter*" because it didn't affect him in all situations or activities. Harry also played down the importance of his difficulties, commenting that no-one was perfect because "*everyone finds some things difficult*". There was a contradiction in Harry's accounts however, as he described occasions when the consequences of his difficulties were very significant and damaging to his emotional well-being. Harry's relationship with dyspraxia was complex and strongly influenced by context and the responses of others.

Participants felt different, but not that different to their peers, and although they described many challenges in their daily lives, they felt better off than people whose difficulties were more severe or life-threatening:

George: It's not life or death.

David: People can make a big fuss of it and I'm not bothered. It's not life or death really.

David was keen to play down his difficulties and was frustrated and embarrassed when others drew attention to them. While he appreciated that help and support from his mum and school enabled his performance and participation, he just wanted to be allowed to just get on with his life without fuss. When he was made to feel different, dyspraxia became a frustration and an embarrassment. Billy was similarly irritated and annoyed when adults drew attention to his difficulties:

Billy: I don't necessarily like it when people talk to me about dyspraxia and how that's affecting me because personally I can't do much about it and that's just who I am.

While Billy and David accepted their diagnosis privately or with close friends and family who were accepting and understanding, they felt stigmatized and embarrassed when they were labelled as dyspraxic by others in a public setting. Some participants however, recognised that having a 'label' enabled them to access support and resources. Accepting that her learning needs were different to those of her peers meant Freya was willing to accept help from the school special needs support team. For her, the benefit of receiving appropriate help and support was greater than the stigma of being different:

Freya: I don't mind having it (*dyspraxia*) because it just means that when you go to different things, at tests you get a little bit longer and things like that.

Eden's perspective was similar and when asked what the term dyspraxia meant to him, Eden responded:

Eden: I get to use a laptop at school.

Accepting a diagnosis of dyspraxia enabled Freya and Eden to adapt to their difficulties by accessing resources and support. Participants' acceptance of dyspraxia was therefore affected by the actual or perceived reaction of others to their difficulties and by balancing the potential social costs against the possibility of being able to reach their potential because of the accommodations that were available to them.

Participants' accounts suggest that their acceptance and understanding of dyspraxia evolved over time. By 15 years of age Billy acknowledged that he had become "*a lot more relaxed*" about his diagnosis:

Billy: I don't see that the diagnosis is that important to me, but it doesn't bother me either way that I've got dyspraxia... Without me being clumsy then I wouldn't be who I am.

Rather than denying or attempting to disassociate himself from the condition, Billy had learned to accept his coordination and organisational difficulties as part of his identity and character. He had learned to like the part of his character that could laugh at his own misfortune and mistakes, and was encouraged by friends who laughed along with him. By 15 years of age, David also accepted dyspraxia as something that he had to learn to live with; he was determined that it was not something that should get in the way:

David: I know I'm never gonna get rid of it, you just have to learn to deal with it.

Freya's perspective was similar and is reflected in her statement that "*It's just me*". Freya was different to most other participants, however, in that she was diagnosed with verbal dyspraxia when very young. Although not initially aware that the support and therapy she received was related to her verbal and motor dyspraxia, she had been consciously living with the diagnosis for longer than the other participants. As a consequence, she seemed to have integrated the diagnosis into her sense of identity and despite the challenges it presented, she was determined to not let it get the better of her. Freya's perseverance and determination to succeed was a further demonstration of her positive adaptation to the diagnosis:

Freya: Just because somebody has told you that you can't do something doesn't mean that you can't do it, because like the doctors and stuff said that I wouldn't be able to drive and things like that, but now they are saying that I will be able to.

While participants felt powerless to change some of their inherent difficulties such as poor handwriting, their responses demonstrated a resilience and optimism that they would be able to achieve activities and take on roles that were important and meaningful to them now and in the future.

Disclosure

This final secondary theme explores participants' willingness to disclose their diagnosis to others. Whatever their personal relationship with dyspraxia, there were situations when participants had to choose whether or not to disclose their diagnosis; such decisions were influenced by confidence in their ability to articulate the condition and by the anticipated reactions of others. Participants were more confident about admitting their diagnosis when the risk of disclosure was reduced because they had known someone for a long time or they were more accepting and understanding of people who were a little bit different. Participants were concerned however, that their reluctance to disclose their diagnosis helped to perpetuate the mystery surrounding dyspraxia as a hidden disability.

While participants felt accepted by close friends despite, or indeed because of their differences, they were ambivalent about telling them that they had dyspraxia. Adam was uncertain about whether or not to tell his friend:

Adam: I'm not sure, I, if I, if I do have dyspraxia I'll, I'm not sure, I might tell him, I might not.

Adam was unsure about what dyspraxia meant and doubted his ability to explain it to others. He was also concerned that telling his friend might affect their relationship, leaving him socially isolated at school. Billy and George also lacked a clear definition of dyspraxia which made it hard for them to explain their diagnosis. Furthermore, when they did disclose that they had dyspraxia they felt the term meant little to their peers:

Billy: He knows I'm dyspraxic but he doesn't know what it means.

George: Most people know that dyslexia's something to do with reading and writing. If you ask someone what dyspraxia is they won't know what it is.

Rather than helping others to understand their condition, Billy and George worried that disclosing their diagnosis added to peers' perception of them as strange because they did not understand dyspraxia or thought the term meant something else.

The desire to avoid standing out strongly influenced participants' decision about whether or not to tell peers that they had dyspraxia. Participants were concerned that admitting to their difficulties might lead to rejection by people who wouldn't want to be associated with someone who did not conform to socially-accepted norms. Callum's reluctance to disclose was fuelled by previously experienced negative reactions and scepticism:

Callum: They thought like I'd made it up you know? 'Cos they don't really know what it is.

Peers' doubts about his honesty and integrity meant Callum was reluctant to expose himself to possible ridicule and social exclusion. Likewise David was worried about telling people that he had dyspraxia in case they bullied him for being different. Billy was reticent about disclosing his diagnosis to his wider peer group because he didn't want to draw attention to characteristics that weren't immediately obvious. By 15 years of age however, he accepted dyspraxia as an integral part of his character and was open with close friends about his diagnosis. Furthermore, when he did have occasion to tell others he felt they were curious rather than dismissive or teasing:

Billy: Most people like, if I say "Oh, I've got dyspraxia" they're inquisitive about it as well.

Harry's decision to disclose his diagnosis to peers was influenced by the possible risk to their relationship. He felt that the risk was reduced if he had known someone for a long time as it was unlikely that he would be rejected when they had previously accepted his quirks and characteristics:

Harry: It matters how well I know them and if they've got dyspraxia as well.

Like Harry, George felt that people who valued difference as well as sameness, including those who had their own additional needs were more accepting; he was therefore more willing to disclose his diagnosis in these circumstances:

George: Some of them that's like dyslexic or got other like problems, like I think are more understanding of it.

Away from school however, participants felt there was little need for people to know that they had dyspraxia unless they needed some help or understanding to accommodate their difficulties:

Billy: I can't think of many people outside of school that even know or need to know and if they do it doesn't really make a difference.

David: I wouldn't know what I'd tell them to be honest. I ain't got a reason to, you know what I mean?

None of the participants had heard the term 'Developmental Coordination Disorder' but when the term was suggested as an alternative to dyspraxia several expressed concern that changing the name would increase confusion and uncertainty both for those affected by the condition and amongst the general public:

George: I think if you start changing the name you're basically back to square one, so I think just keep it as dyspraxia.

"Square one" for George was a situation characterised by societal ignorance and discrimination against those who were different. George was frustrated by poor public awareness of dyspraxia. This affected his willingness to disclose his difficulties, but he was also conscious that his reluctance helped to perpetuate dyspraxia as a hidden disability. By participating in this study however, he felt he was able to help increase understanding and raise awareness of the condition without drawing attention to himself as an individual. George was optimistic for the future and was encouraged by knowing that public awareness had helped to increase acceptance of other developmental conditions:

George: At one point dyslexia was unknown, like autism and stuff, but now obviously people know what it is and accept it as part of what people are. So if that can come across in the next 10 years for dyspraxia that's a big step.

Summary of master theme 5

In this theme, it was evident that participants experienced learning about their diagnosis as a process rather than an event; moreover it was a process characterised by a sense of confusion, uncertainty and isolation. Participants' confusion was not immediately relieved on learning that there was a name for their difficulties as the term dyspraxia had little meaning for them and they were unable to compare their experiences with those of others who had dyspraxia. Participants' relationship with dyspraxia varied over time and context and was influenced by their personal understanding of the diagnosis, its impact on their daily life activities and by the reactions of others, both real and anticipated. Some coped by distancing themselves from the label while others were relieved to find a legitimate explanation for their differences. The different experiences highlighted in this study suggest that adjustment to and acceptance of dyspraxia as part of a person's identity is a complex process that cannot be accounted for simply by a person's age or by the severity of their difficulties.

Chapter Conclusion

This chapter presented key themes drawn from the testimonies of a group of teenagers that illustrate the lived experience of DCD/dyspraxia. The first theme revealed that teenagers experienced DCD/dyspraxia to be more than just a motor impairment. While participants shared many examples of their coordination difficulties and their impact on activities of daily living, they also attributed poor organisational, planning and time management skills to their diagnosis. Themes two and three illustrate the social and emotional impact of DCD/dyspraxia, while the fourth theme offers insight into participants' school experience. The final theme demonstrates how participants attempted to make sense of their diagnosis and the impact this had on their sense of identity over time. In the next chapter I consider these findings in the context of literature presented in Chapter 2 and the wider disability and chronic illness literature.

Chapter 6

Contextualising the Findings

Chapter 6: Contextualising the findings

In this chapter I review the study findings and consider these in the context of the extant qualitative literature concerning people with DCD/dyspraxia and in relation to the wider disability and chronic illness literature that has a particular focus on teenagers. Three main themes emerged from the review of qualitative literature examined in Chapter 2: participation in sports and physical activity; relationships with peers; and developmental trajectories through adolescence. These themes were evident in the narratives of participants in the current study and are encompassed in the themes described in Chapter 5. In Chapter 6 I will consider each of the five themes described in Chapter 5 in the context of the extant qualitative literature. The chapter concludes with a review of the extent to which the study findings support or challenge previous research narratives.

The first theme described in Chapter 5 “*Doing everything the hard way*” highlighted the extra effort required for teenagers with DCD/dyspraxia to perform everyday activities compared to their physically able peers. David and George were particularly frustrated and embarrassed at their inability to manage daily tasks such as using cutlery and tying shoe laces. These activities were also identified as problematic by parents in a study by Missiuna et al (2006a) who highlighted that children with DCD/dyspraxia required more time and support to master basic self-care activities and were older than their peers before they were able to perform these tasks independently. Parents in a study by Stephenson and Chesson (2008) recognised the sense of shame and embarrassment these difficulties caused their children, emotions which are reflected in the narratives of participants in the current study. Findings from the present inquiry extend this finding, indicating that continued failure to manage basic skills had a devastating impact on some participants’ sense of worth and self-esteem. This finding supports the perception of parents (Mandich, Buckolz and Polatajko 2003) who reported that failure to master “*seemingly unimportant*” everyday activities had significant social and emotional consequences for their children (p588). Like teenagers with other motor disorders, chronic illness and disability (Dovey-Pearce, Doherty and May 2007, Shikako-Thomas et al. 2009), participants in the current study seemed more frustrated by the functional and social impact of their motor difficulties than their condition itself. This is of note as the extant literature is biased towards measures of performance components such as balance and eye-hand coordination rather than functional activities which, as the findings of this study illustrate, are the primary concern of young people with DCD/dyspraxia.

Participants in the present inquiry were embarrassed at their reliance on their parents at a time when they expected to become more independent, a perception shared by teenagers with DCD/dyspraxia in the study by Lingam et al (2014). Teenagers with diabetes (Dovey-Pearce, Doherty and May 2007) were similarly uncomfortable at their need for ongoing parental support to help

manage their diet, although like participants in the present study they appreciated the safe haven that the family home provided. Tensions between participants and their parents found in this study are reflected in the narratives of parents (Missiuna et al. 2006b, Summers, Larkin and Dewey 2008) who described their struggle to reconcile the need to facilitate independence whilst ensuring that tasks were performed in a timely manner. What this study has revealed however is that teenagers with DCD/dyspraxia were willing to invest time and effort to master activities that were important to them and that they appreciated being provided with opportunities to practice skills in a supportive environment. Moreover, findings from the current study support those reported by Lingam et al (2014) indicating that successfully performing seemingly trivial tasks boosted teenagers' self-esteem and enhanced their image as a capable person. The experience of teenagers with DCD/dyspraxia is similar to that of teenagers with cerebral palsy (King et al. 2000) who reported that accomplishing small things promoted a sense of success and happiness. Findings from the present inquiry indicate however, that teenagers with DCD/dyspraxia were anxious about mastering more complex life skills associated with adulthood, reflecting the concerns of parents (Missiuna et al. 2007, Novak et al. 2012) who were anxious about their child's ability to cope with changing environmental contexts and increased social and academic expectations during adolescence. The fears of participants in the current study reflect the actual experience of adults with coordination difficulties (Kirby, Edwards and Sugden 2011, Missiuna et al. 2008a) who described their struggle to learn new motor tasks associated with adulthood such as driving a car.

Handwriting was identified as a particular challenge by participants in the present inquiry, echoing the experience of teenagers with DCD/dyspraxia in the study by Lingam et al (2014) and the perceptions of both parents (Missiuna et al. 2006b) and teachers (Missiuna et al. 2006a). Parents (Missiuna et al. 2006b) shared the frustration and disappointment experienced by participants in the current inquiry when their child's work was marked down for its poor presentation. Like some adults (Missiuna et al. 2008a) however, participants felt that handwriting became less of an issue over time as expectations changed and there were more opportunities to type rather than write assignments.

Participation in sports and physical activity was one of the three main themes that emerged from a review of the extant quantitative literature described in Chapter 2; this is not unexpected as DCD/dyspraxia is defined as a motor coordination disorder (American Psychiatric Association 2013). DCD/dyspraxia however, has a much less obvious impact on people's ability to engage in physical activity than for example cerebral palsy or muscular dystrophy, yet in some cases participants' comparatively mild motor difficulties had a significant impact on their motivation to engage in sport and physical activities. Participants' experience supports previous research indicating that prior

failures and negative experiences have an enduring impact on the confidence and motivation of people with DCD/dyspraxia to engage in physical activities (Fitzpatrick and Watkinson 2003, Missiuna et al. 2008a). Similar to adults in the study by Fitzpatrick and Watkinson (2003) participants experienced feelings of humiliation and embarrassment at their failure to adequately perform physical tasks that their peers managed easily; moreover, anxiety about exposing their coordination difficulties inhibited their willingness to get involved. Parents were similarly anxious about the risk of humiliation and some limited their child's participation in organised sports to protect their self-esteem (Missiuna et al. 2006b, Missiuna et al. 2007). There is however a tension between parents' reactions and the perceptions of some teenagers in the current study who, like young people in studies by Barnett et al (2013) and Lingam et al (2014), wanted to participate in sport to develop their physical skills and were keen to identify an environment that was a good match for their motor abilities. This finding highlights the importance of eliciting teenagers' views which may be different to those of their parents. Furthermore, assuming that teenagers with DCD/dyspraxia don't want to participate in sports and physical activity could limit opportunities for motor skill and social development.

The second theme described in Chapter 5 as *"I didn't want to be seen as someone different"* encompasses another of the three main themes emerging from the review of extant qualitative literature examined in Chapter 2. Fear of being different is a common theme in qualitative studies involving young people with other disabilities and chronic conditions including autism (Huws and Jones 2008), juvenile idiopathic arthritis (Tong et al. 2012) and diabetes (Dovey-Pearce, Doherty and May 2007). Similar to adults with poor coordination (Missiuna et al. 2008a) participants in the current study felt marginalised and excluded by peers when they were unable to meet expected performance standards because of their motor difficulties, a situation which also saddened parents (Mandich, Polatajko and Rodger 2003, Segal et al. 2002). What the current study has revealed is that fear of being stigmatized because of their differences affected participants' willingness to engage in certain activities because of the unwanted attention this might attract, an experience also shared by adults with poor motor coordination (Fitzpatrick and Watkinson 2003). By contrast, participants valued friends who accepted them, who shared their interests and who provided them with practical and emotional support. This view is similar to that of teenagers with DCD/dyspraxia in the study by Lingam et al (2014) and young people with cerebral palsy (Shikako-Thomas et al. 2009) who, like some participants in the present study, enjoyed participating in adapted activities alongside others with similar difficulties and abilities as this provided a safe place to develop their confidence and skills.

As described in Chapter 2 social outcomes for teenagers with childhood motor difficulties have been reported previously in the qualitative literature from the perspective of teenagers (Lingam et al. 2014) and parents (Stephenson and Chesson 2008). The social vulnerability evident in the narratives of Callum and Harry described in Chapter 5 reflects the experience of teenagers with other needs including adolescents with facial disfigurement (Prior and O'Dell 2009) and cerebral palsy (Lindsay and McPherson 2012) who felt socially excluded and were bullied by teachers and peers. Findings from the present inquiry suggest that social exclusion occurs because of adults' poor awareness, knowledge and understanding of teenagers' difficulties, an experience shared by young people with cerebral palsy (Lindsay and McPherson 2012). Students with cerebral palsy (Lindsay and McPherson 2012) however, faced additional challenges because they were physically isolated from peers by an inability to access all parts of the school environment and had fewer opportunities to make friends because of a lack of inclusive activities.

Research conducted by Stephenson & Chesson (2008) revealed that parents of children with DCD/dyspraxia believed that the risk of bullying and victimisation increased during the transition to senior school as peers became more aware of the limitations of others during adolescence. While parents interviewed by Missiuna et al (2007) grew more concerned for their child's psychosocial well-being as they grew older however, findings from the current study suggest that social pressures lessened for some participants as they learned to manage their coordination difficulties. Similar to adults in the study by Missiuna et al (2008a) Billy and George felt the pressure towards conformity reduced over time and their personality 'quirks' were more accepted by significant peers as they matured.

The emotional impact of living with DCD/dyspraxia as a teenager emerged as a strong theme in this study and encompasses the theme of developmental trajectories that emerged from the literature review described in Chapter 2. This reflects findings from previous qualitative research involving young disabled people (King et al. 2000) and adolescents with chronic medical conditions including those with diabetes (Hema et al. 2009) and juvenile chronic arthritis (Stinson et al. 2008). The emotional impact of living with DCD/dyspraxia as a teenager also emerges as a strong theme in parental research (Missiuna et al. 2006a, Missiuna et al. 2007, Stephenson and Chesson 2008). In these studies parents highlighted the frustration their children experienced when they were unable to perform tasks as they wanted, describing their lives as being "*full of challenges and frustrations*" (Missiuna et al. 2007). Some parents in the study by Missiuna et al. (2007) described their child's frustration building over time leading to angry outbursts like that described by Ian in Chapter 5. Others parents in Missiuna et al's (2007) study sensed that their children felt overwhelmed by the

expectations and work required of them and internalized their anxiety, reflecting the experience of participants in the present study who felt under constant pressure at school. As revealed by Missiuna et al (2007) however, some parents felt their children 'masked' their problems by putting in extra effort so that their difficulties weren't noticed, a strategy adopted by Billy and Freya and described in Chapter 5. David's guilt and sadness at the impact of his emotional outbursts on his family echoes that of mothers (Novak et al. 2012, Stephenson and Chesson 2008) who felt guilty at their lack of patience and who were emotionally drained by the extra support and time that children with DCD/dyspraxia needed.

Findings from the current study reveal that participants' self-esteem was significantly affected by their interactions with teachers, a phenomenon also experienced by young people with dyslexia (Glazzard 2010) and cerebral palsy (Lindsay and McPherson 2012). Present study findings further indicate that public experience of failure and unthinking comments from teachers led to intense feelings of shame and humiliation, an experience shared by teenagers with dyslexia (McNulty 2003). Like teenagers with DCD/dyspraxia in the study by Lingam et al (2014) teenagers in the current study worked hard to improve skills that were important to them; furthermore being successful enhanced their self-esteem.

Adults and teenagers with coordination difficulties in studies by Missiuna et al (2008a) and Lingam et al (2014) employed a range of strategies to help them cope with their difficulties, corresponding with approaches adopted by participants in the present inquiry. A common coping strategy adopted by adults with coordination difficulties (Fitzpatrick and Watkinson 2003) also described by participants in the current study was to avoid or withdraw from activities that required good physical coordination; this coping strategy was also reported by parents in Stephenson and Chesson's inquiry (2008). Findings from the current study further reveal that participants coped by identifying activities and contexts that were a better match for their abilities, a strategy also adopted by adults with poor motor coordination (Missiuna et al. 2008a).

As highlighted in Chapter 5, Billy used humour as a way of minimising his coordination difficulties, a coping strategy also employed by some adults with coordination difficulties (Missiuna et al. 2008a). While Semrud-Clikeman et al (2010) concluded that having a sense of humour is important for the likeability and peer-acceptance of adolescents, little is known about the use of humour in young people with disabilities and whether or not this supports their emotional well-being. Findings from the current study suggest that the use of humour as a coping strategy by teenagers with DCD/dyspraxia and its impact on emotional resilience during adolescence is an area worthy of further investigation.

This study fills an important gap in understanding of the school experience of teenagers with DCD/dyspraxia from their own perspective. Participants felt let down by teachers who lacked awareness and understanding of their condition and who misinterpreted their difficulties as laziness or disinterest. Their concern is shared by parents (Missiuna et al. 2006a) who described their children as ‘missed and misunderstood’ in the classroom. Participants in the present inquiry felt that teachers needed more training to understand their needs, a perception shared by teenagers with Asperger’s Syndrome (Humphrey and Lewis 2008). Even though participants in the present study described some teachers as interested and supportive, their experience suggests that general strategies for people with DCD/dyspraxia did not always have a positive impact on their learning and participation. This finding supports the experience of female students with physical disabilities (Erten 2011) who considered that understanding a condition theoretically was not the same as dealing with a person individually.

The current study highlighted David and Billy’s frustration when prevented from using strategies and accommodations that supported their performance. Their experience reflects that of students with physical impairments (Egilson and Traustadottir 2009) who were frustrated when teachers struggled to vary their teaching methods to accommodate their needs. As revealed in Chapter 5, participants felt disadvantaged by school systems that prioritised the needs of students with other difficulties, a view shared by parents (Rodger and Mandich 2005) who felt frustrated and angry because their children were not a priority for extra help. A common theme in parent-focused studies is that of having to ‘fight the system’ to access support (Missiuna et al. 2006a, Novak et al. 2012, Stephenson and Chesson 2008). While parents described battling with organisations and systems, findings from the current study reveal that participants were battling with the actions and responses of individual teachers. As with parents in the inquiry by Novak et al (2012) participants in this study were frustrated at the lack of recognition given to their knowledge as experiential experts, a situation which left them feeling angry and disempowered. By contrast and like teenagers with cerebral palsy (Shikako-Thomas et al. 2009), participants in the current study felt empowered when able to advocate for themselves and use accommodations they had chosen. Self-awareness was identified by students with physical disabilities (Erten 2011) as a factor contributing to their academic achievement, supporting the current study finding that teenagers who understood their personal needs were more able to identify and use accommodations to enable them to be successful at school.

Similar to adolescents with Asperger’s Syndrome (Humphrey and Lewis 2008) and teenagers with cerebral palsy (Lindsay and McPherson 2012), participants struggled to reconcile their need for

equipment such as a laptop with the risk of this highlighting their differences. Current study findings suggest that negative consequences such as unwanted peer attention might lead teenagers with DCD/dyspraxia to reject equipment even if it improved their school performance. Their experience is similar to that of students with physical disabilities (Hemmingsson, Lidström and Nygård 2009) who evaluated assistive technology from a psychosocial perspective as well as a functional one. As described in Chapter 5, the willingness of some participants to accept in-class support from a teaching assistant was also influenced by psychosocial factors. While several participants in the current inquiry felt reassured by the presence of general classroom helpers who provided subtle assistance to all students, most felt that the social disadvantages of having an individual support assistant outweighed the benefits, a perception shared by adolescents with Asperger's Syndrome (Humphrey and Lewis 2008). The experience of adolescents with Asperger's Syndrome and participants in the current study is similar to young people with cerebral palsy (Lindsay and McPherson 2012) who acknowledged that while having an education assistant was helpful, it also perpetuated their isolation and exclusion from peers. Similar to students with mild learning difficulties (Knesting, Hokanson and Waldron 2008) however, Adam accepted having in-class support because this helped him to achieve at a level that reflected his ability. What this study has revealed is that organisational solutions to support young people with DCD/dyspraxia are often ineffective and in some cases make life harder. Understanding the perspectives of young people with DCD/dyspraxia will provide information that can guide the development of school systems and accommodations that support, rather than inhibit their academic and personal development.

Participants in the current study highlighted the impact of DCD/dyspraxia on their sense of identity, an issue also identified by Lingam et al (2014). Teenagers in both studies varied in their perceptions of the impact of DCD/dyspraxia on their sense of self, reflecting differences in the personal accounts of adults with coordination difficulties (Missiuna et al. 2008a). Many participants in the present study felt different to their peers before they learned of their diagnosis, an experience shared by people with other 'hidden' disabilities including young people with dyslexia (McNulty 2003) and Asperger Syndrome (Portway and Johnson 2005). Teenagers with juvenile chronic arthritis also described feelings of isolation and feeling different from others (Stinson et al 2008). Participants in the current study did not however, express strong emotions about receiving a diagnosis of DCD/dyspraxia unlike young people with autism (Huws and Jones 2008) who described feelings of shock, disappointment and disbelief. The absence of strong negative emotions may be accounted for by participants' lack of preconceptions about the diagnosis of DCD/dyspraxia; instead the current study reveals that they were curious about what the diagnosis meant. Indeed, most participants were relieved to discover there was a legitimate explanation for their difficulties, an emotion shared

by some parents (Missiuna et al. 2006b) and by people with dyslexia (Armstrong and Humphrey 2009) and diabetes (Dovey-Pearce, Doherty and May 2007). The experience of receiving a diagnosis of diabetes (Dovey-Pearce, Doherty and May 2007) is however different to the experience of receiving a diagnosis of DCD/dyspraxia because being diagnosed with diabetes represents a shift from a position of 'health' to one of 'ill-health'. While teenagers with DCD/dyspraxia in the current study were concerned about the functional impact of their coordination difficulties, teenagers with diabetes worried about the impact of their diagnosis for their future health and mortality (Dovey-Pearce, Doherty and May 2007).

Findings in Chapter 5 revealed that participants' adjustment to their diagnosis was affected by the reactions of others. Similar to teenagers with diabetes (Dovey-Pearce, Doherty and May 2007) and juvenile chronic arthritis (Stinson et al. 2008) participants in the present inquiry had varying experience of disclosing their diagnosis to peers. Participants were willing to accept their label of DCD/dyspraxia in private and in the company of family members and close friends, but were resistant to the label being applied by others to them in a public setting, a feeling shared by teenagers with dyslexia (Armstrong and Humphrey 2009). Young people with cerebral palsy were similarly embarrassed when attention was drawn to their difficulties unnecessarily (Shikako-Thomas et al. 2009).

Participants in the present inquiry acknowledged their difficulties, but like people with dyslexia (Armstrong and Humphrey 2009) and teenagers with DCD/dyspraxia in the study by Lingam et al (2014) did not define themselves by their diagnosis. Most participants in the current study regarded clumsiness as a personal characteristic, a perception also shared by adults with motor difficulties (Missiuna et al. 2008a). Participants were keen to stress that DCD/dyspraxia was not something that affected everything that they did, all of the time. This view is shared by young people with cerebral palsy (Shikako-Thomas et al. 2009) who considered themselves to be normal people who just happened to have a disability, and young people with epidermolysis bullosa simplex (Williams, Gannon and Soon 2011) who described themselves as normal in spite of their appearance. Findings from the current study suggest that participants who had known about their diagnosis for a long time were more accepting of their diagnosis, reflecting the experience of young people with dyslexia (Armstrong and Humphrey 2009) and the experience of Hughes (2012) who described his eventual acceptance of his autism as "*something that was part of me*" (p97) rather than something separate.

How do the study findings support or challenge previous narratives?

So far in this chapter I have considered the study findings in the context of the extant qualitative literature presented in Chapter 2 and the qualitative literature regarding teenagers with other

disabilities or chronic illness. In this section I consider the extent to which the study findings support or challenge these previous research narratives. I first compare the study findings with the extant literature examining the lived experience of DCD/dyspraxia from the perspective of teenagers, adults and parents, before moving on to consider similarities and differences between the narratives of participants in the present study and those of teenagers with other disabilities or chronic illness.

As illustrated in Chapter 2, only three previous studies report the lived experience of teenagers with DCD/dyspraxia from their own perspective, one of which reports initial findings from the present study (Payne et al. 2013). Research by Barnett et al (2013) focused specifically on teenagers' perceptions of constraints and facilitators to participation in physical activity; however like teenagers in the study by Lingam et al (2014) the narratives of participants in the current study placed greater emphasis on the challenges they experienced with everyday tasks such as using cutlery than on their physical ability. This is of note as the extant literature regarding DCD/dyspraxia (which is mainly quantitative) is biased towards studies of motor impairment and perceptions of motor competence rather than the functional daily activities which the findings of the current study suggest are of greater concern to teenagers living with DCD/dyspraxia.

There are many parallels between the narratives of teenagers in the current inquiry and those reported by Lingam et al (2014). While participants in both studies shared the same diagnosis, findings suggest considerable variation in the impact of DCD/dyspraxia between individuals. Similar to teenagers in Lingam's study (2014) participants in the current inquiry described both physical and non-motor difficulties that had a negative impact on their daily lives functionally, socially and academically. While some participants in each study doubted their academic competence, others considered themselves to be academically able. Findings from both studies also indicate a developmental trajectory, suggesting that DCD/dyspraxia had more of an impact on younger teenagers. What findings from the present research reveal however is that older teenagers benefitted from greater self-awareness and more opportunity to use strategies that enabled their performance at home and at school. Narratives from both studies further indicate that teenagers with DCD/dyspraxia were willing to work hard to improve their skills and that even small successes were important for their self-esteem and sense of identity.

Findings from the current study support the narratives of adults with poor motor coordination (Fitzpatrick and Watkinson 2003) who experienced a sense of hurt and humiliation when their motor difficulties were publically exposed. Findings from adult research (Fitzpatrick and Watkinson 2003) further reveal that these negative emotions were enduring and persistent. Fears reported by teenagers in this inquiry and previous research (Lingam et al. 2014) regarding the challenge of

managing future skills are supported by the experience of adults with motor difficulties (Kirby, Edwards and Sugden 2011, Missiuna et al. 2008a) who struggled when learning to drive and managing new skills in the workplace. However, findings from adult studies (Kirby, Edwards and Sugden 2011, Missiuna et al. 2008a) support the view of participants in the present inquiry that their difficulties were not all pervasive and were influenced by performance expectations and the context in which activities took place.

Chapter 2 revealed a bias in the extant qualitative literature towards reporting parents' perceptions of the lived experience of DCD/dyspraxia (Mandich, Polatajko and Rodger 2003, Missiuna et al. 2006a, Missiuna et al. 2006b, Missiuna et al. 2007, Novak et al. 2012, Stephenson and Chesson 2008). Prioritizing parental perspectives assumes that parents are accurate informants on the lived experience of DCD/dyspraxia; what the review of extant literature has revealed however is that this is not necessarily the case. Moreover, participants in the present inquiry were frustrated when their views as experiential experts were disregarded or dismissed by adults. Narratives of participants in the present inquiry were generally more optimistic and positive than those of parents reported by Missiuna et al (2007) and Stephenson and Chesson (2008), a finding also noted by Lingam et al (2014). Likewise, young people with cerebral palsy (Shikako-Thomas et al. 2009) were more optimistic than their parents. Current study findings therefore highlight that while parent-focused studies offer valuable insights into the social context in which adolescents live, neglecting to consider teenagers' own perspectives risks limiting understanding of teenagers' lived experiences and how these contribute to their success or difficulties in later life.

There were similarities between the narratives of participants in the current study and teenagers with chronic conditions including diabetes (Dovey-Pearce, Doherty and May 2007, Hema et al. 2009) and juvenile arthritis (Stinson et al. 2008, Tong et al. 2012). The experiences of teenagers in the current study were however qualitatively different to those of teenagers with diabetes (Dovey-Pearce, Doherty and May 2007) who had to accommodate new activities into their daily routine and consider their future as someone with long term health needs. Teenagers in the current study and those with diabetes (Dovey-Pearce, Doherty and May 2007) and arthritis (Tong et al. 2012) were however, similar in their need for support from their family and shared a fear of being excluded or stigmatized which influenced whether or not they decided to disclose their diagnosis to others. While the present inquiry revealed that some participants with DCD/dyspraxia felt excluded and marginalised by peers, findings also echo the experience of some adolescents with chronic juvenile arthritis (Stinson et al. 2008) who reported that peer support helped them to cope with the consequences of their condition.

There were similarities between the narratives of participants in the current study and those of young people with cerebral palsy (King et al. 2000, Lindsay and McPherson 2012, Shikako-Thomas et al. 2009). It was interesting to note however, that the severity of physical limitations was not necessarily associated with teenagers' psychosocial well-being. Like young people with cerebral palsy (Shikako-Thomas et al. 2009) the narratives of participants in the present inquiry suggest that their participation in social activities, mastery of skills and perceptions of social support had more influence on their sense of identity and well-being than the level of physical disability.

Narratives of participants in the present study were perhaps most similar to those of teenagers with other 'hidden' developmental disabilities including young people with dyslexia (Armstrong and Humphrey 2009) and autism or Asperger's Syndrome (Humphrey and Lewis 2008, Huws and Jones 2008). Although difficulties experienced by young people with 'hidden disabilities' are present from birth, findings from the current study reveal that participants' awareness of their difference emerged over time. Similar to teenagers with facial disfigurement (Prior and O'Dell 2009), arthritis (Stinson et al. 2008) and dyslexia (Armstrong and Humphrey 2009) participants in the present inquiry valued knowing others with similar experiences. What this research has revealed however is that it was hard for teenagers with DCD/dyspraxia to actually identify people who shared their diagnosis and that this increased their sense of isolation.

Chapter Conclusion

This chapter placed participants' experience in the context of extant qualitative literature concerning people with DCD/dyspraxia, and the wider literature concerning adolescents with chronic illness and disabilities. Examining similarities and differences between these narratives has allowed deeper insight into and understanding of the lived experience of teenagers with DCD/dyspraxia. In the following chapter new understandings brought forth in this study are drawn together into a conceptual framework that represents the lived experience of teenagers with DCD/dyspraxia.

Chapter 7

Conceptual Framework

Chapter 7: Conceptual Framework

Introduction

This study set out to develop an understanding of how life is experienced by teenagers with DCD/dyspraxia. In Chapter 5 key themes derived through the process of interpretative phenomenological analysis were presented. Analysis was supported by the inclusion of direct quotes to illustrate themes and to ensure the centrality of the participants' voice. In Chapter 6 these findings were considered in the context of the extant qualitative literature. This process highlighted a number of common themes between the accounts of participants as described in Chapter 5 and previous narratives of adults and teenagers with DCD/dyspraxia, their parents and teenagers with chronic illness or disability.

This chapter builds on these themes and narratives, offering novel insights into the lived experience of DCD/dyspraxia as they emerged during the research process. These insights are drawn together into a conceptual framework which is presented as a new and exciting means of demonstrating the complex interaction of factors representing the lived experience of teenagers with DCD/dyspraxia. The conceptual framework will be of benefit to occupational therapists, professionals working in health and education, the Dyspraxia Foundation and teenagers themselves, as it offers a way of thinking about the functional domains of concern to teenagers, the personal and environmental factors that influence teenagers' performance of everyday activities, and the impact of teenagers' efficacy beliefs on their personal development and sense of self as they make the transition towards adulthood.

I begin by demonstrating how my understanding of the meanings that teenagers attach to their experience of living with DCD/dyspraxia developed during the research process, and how these were drawn together into a conceptual framework. I then examine each component of the conceptual framework (Figures 7 to 11) and show how these build to create the conceptual framework as a whole (Figure 11). I conclude the chapter by proposing an occupational therapy model of practice as a means of applying the conceptual framework in practice.

Developing the conceptual framework

The nature of this study offered a unique opportunity for prolonged engagement with individual accounts, the building of narratives for participants who engaged in multiple interviews, and the development of themes and concepts over an extended period of time. Each hermeneutic cycle enabled a deeper understanding of participants' experience which was further enhanced by insights offered by the Reference Group. The conceptual framework evolved during the analytical process as potential patterns and connections across findings were revealed. Drawing on literature and

discussing ideas with my supervisors, the Reference Group and colleagues, helped to develop my understanding of the lived experience of teenagers with DCD/dyspraxia as a whole.

Conceptual frameworks are defined as *“a network ... of interlinked concepts that together provide a comprehensive understanding of a phenomenon or phenomena”* (Jabareen 2009). Attempting to create, for the first time, a conceptual framework of the lived experience of teenagers with DCD/dyspraxia was both challenging and overwhelming at times. However, I also feel excited by the possibilities that this new way of thinking opens up for parents, professionals and organisations such as the Dyspraxia Foundation to provide more effective support for teenagers with DCD/dyspraxia in the future. The conceptual framework is, therefore, presented as an original and novel contribution to knowledge about the lived experience of DCD/dyspraxia during adolescence.

Towards the latter stages of the analytical process, two significant and recurring concepts emerged across the findings: social comparison (Festinger 1954) and self-efficacy (Bandura 1977, Bandura 1994, Bandura and Locke 2003). I explored these theories as a means of enlightening the findings and furthering my understanding of participants' lived experience. By linking findings to existing literature, new understandings have emerged which open up possibilities for intervention and practice to enable the personal development and successful participation of young people with DCD/dyspraxia in important areas of function as they make the transition towards adulthood.

Drawing on theories of self-efficacy and social comparison

This section examines the two important theories that informed development of the conceptual framework, highlighting their influence on my understanding of the themes and concepts that emerged.

Social comparison theory

Social comparison (Festinger 1954) emerged as a significant concept across the findings presented in Chapter 5. Participants' accounts indicate that they compared themselves to older and younger siblings, to peers with and without additional needs and, in some cases, to their parents. Social comparison influenced participants' capability perceptions, the amount of effort they were prepared to invest in an activity, their relationship with others, and their sense of identity.

Social comparison theory (Festinger 1954) explains the process by which individuals evaluate their opinions and abilities by testing them against others', and the influence of this on their identity development and behaviour. According to Festinger's thinking, people consciously compare themselves to similar others as a way of 'benchmarking' their own abilities and opinions. Eden for example, compared his motor coordination and sporting ability to that of his peers and concluded

that he was “*not sporty*”. While Festinger suggested that people chose similar others for comparison, more recent thinking indicates that comparison with dissimilar people also plays an important role in self-evaluation and the formation of self-concept (Suls, Martin and Wheeler 2002). Corcoran et al (Corcoran and Mussweiler 2011) posit that people have different motives for engaging in social comparison. While lateral comparison with similar others facilitates self-evaluation, people who want to enhance or protect their self-view engage in downward comparison with people who are worse off. David, for example, compared his motor difficulties to a peer with cerebral palsy. Upward comparison, when a person compares themselves to someone with better abilities, can provide information about how a person might advance their skills, as demonstrated by Billy’s aspiration to be more organised like his father. However, contrary to Festinger’s original ideas, more recent understanding indicates that social comparison is not always a conscious process (Stapel and Blanton 2004). People also vary in the extent to which they compare themselves to others and how they interpret comparison information (Buunk and Mussweiler 2001). Observations that social comparison affects emotional well-being (White, Langer and Yariv 2006) and is significant in situations when social standing is important (Suls, Martin and Wheeler 2002), are supported by the findings of this study.

Self-efficacy theory

Perceived self-efficacy emerged as a strong and recurring theme across the findings, affecting participants’ motivation for activities, the way in which they dealt with tasks and challenges, and the goals they set for themselves personally, academically and socially. Bandura defined perceived self-efficacy as:

“people’s judgement of their capabilities to organise and execute courses of action required to attain designated types of performances. It is concerned not with the skills one has, but with the judgements of what one can do with whatever skills one possesses” (Bandura 1986).

Participants’ accounts demonstrate that perceived self-efficacy influenced the amount of effort they invested, the activities they chose to pursue, and their emotional and behavioural responses to anticipated or actual scenarios. (Note: for ease of reading the term ‘perceived self-efficacy’ is hereafter shortened to ‘self-efficacy’.)

Self-efficacy is one component of Bandura’s social cognitive theory, a theory highlighting the role of cognition and context on human behaviour (Bandura 1986). Bandura argued that individuals are active players in shaping their life circumstances and do not simply respond to environmental factors (Bandura 1986). He identified four cognitive processes through which individuals influence their life experiences and attainment of personal goals: self-observation (monitoring ones behaviour and

progress towards a goal); self-evaluation (comparing current performance against a desired goal); self-reaction (evaluating one's response to performance) and self-efficacy (Wood and Bandura 1989). Social cognitive theory has been criticised for ignoring the impact of a person's innate ability to observe and learn from their experiences, and for assuming that changes in the environment will automatically lead to changes in behaviour (Flamand 2013), issues which are discussed in the context of this study later in this chapter. In this section I focus on one particular component of social cognitive theory, self-efficacy, as this emerged as a strong and recurring influence on teenagers' lived experience.

Bandura identified four main sources of self-efficacy: skill mastery; social persuasion; modelling and affective responses (Bandura 1977, Wise and Trunnell 2001). He argued that the strongest influence on self-efficacy is mastery: performing a task successfully strengthens a person's perceived efficacy, while failing to adequately deal with a task or challenge undermines and weakens it. According to Bandura (Bandura 1986, Bandura 1994), individuals who have a poor self-efficacy anticipate things going wrong, experience self-doubt and set themselves low standards. When faced with adversity they give up quickly and are slow to recover their self-efficacy following failure or setbacks (Bandura 1994). Bandura argued that while some setbacks are useful in teaching that success requires sustained effort, constant failure undermines a person's belief in their capabilities and will affect their motivation and choice of personal goals (Bandura and Locke 2003).

Bandura's observation that people's behaviour is influenced by their perceived capacity to perform an activity has had a significant impact on psychological theory and research. It has also influenced the development of health education (Lawrance and McLeroy 1986, Strecher et al. 1986) and academic programmes (Schunk 1984, Zimmerman 2000). Bandura's theory is not, however, without its critics. Biglan (1987) argued that an individual's behavioural responses cannot be completely accounted for by efficacy beliefs, and that environmental variables also play a role. For example, he argued that improvements in self-efficacy following a desensitization programme for people with phobias reflect changes in behaviour that were a direct response to treatment (reduced physiological arousal) as well as improvements in efficacy beliefs, thus challenging the assumption that treatment effects occur only because of its impact on efficacy-perceptions. Biglan claimed therefore, that the assumption that all behaviour is a response to cognitions about whether or not a person can do something is exaggerated. More recently Williams (Williams 2010) criticised Bandura's self-efficacy theory for its assertion that there is a causal link between self-efficacy and expected outcomes of behaviour, but not vice versa. Williams cites research (Baker and Kirsch 1991, Corcoran and Rutledge 1989, Kirsch 1982) demonstrating the causal influence of outcome

expectancies on self-efficacy judgements, arguing that this calls into question the validity of Bandura's self-efficacy theory and the findings of previous self-efficacy research. Williams raises further questions about the validity of self-efficacy rating measures, arguing that variations in interpretation of language make it difficult to determine whether individuals incorporated expected outcomes into their efficacy-ratings or not. He argues therefore, that it is difficult to test a hypothesis based on a psychological construct of self-efficacy if that psychological construct is not clearly defined, and the validity of efficacy rating scales is questionable.

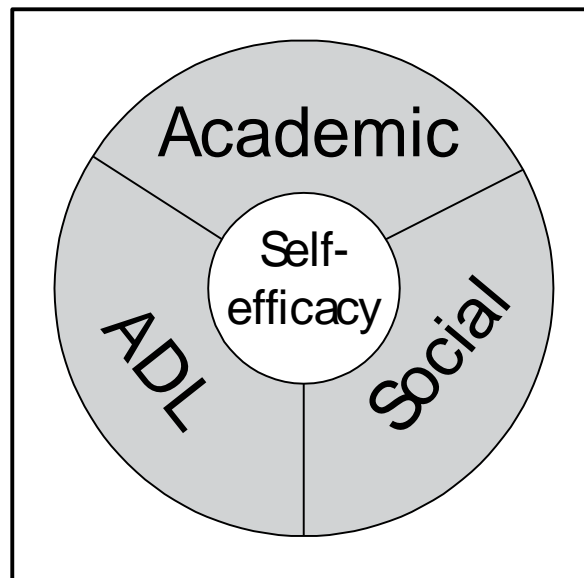
My reflections and discussions with my supervisory team suggested that developing an understanding of the factors that influence and are influenced by teenagers' self-efficacy might offer new insights and opportunities for parents, professionals and organisations such as the Dyspraxia Foundation to enhance the performance and personal development of teenagers with DCD/dyspraxia as they make the transition towards adulthood. Understanding the personal (motor and cognitive capabilities) and environmental (social and contextual) factors that affect self-efficacy opens up the possibility of influencing these factors to enhance an individual's belief in their ability to perform activities that matter to them, and thus their satisfaction with, and performance of, those activities. Interventions might include developing underlying capacity (personal factors) or adapting the physical or social environment in which those activities take place. Understanding the factors that influence self-efficacy might also help to explain observations by parents and professionals that teenagers with similar motor and cognitive abilities participate and perform activities at different levels. Furthermore, enhancing teenagers' sense of efficacy might benefit their personal development in terms of their sense of identity, their emotional well-being, and their sense of agency and ambition. These factors were incorporated into the conceptual framework as 'efficacy-related outcomes'. The complex interactions between factors that influence, and are influenced by, self-efficacy are discussed in the following section. I move on now to describe each component of the conceptual framework in turn, demonstrating through Figures 5 to 9 how these build to create the conceptual framework as a whole.

Self-efficacy as the central concept

Self-efficacy is placed at the centre of the conceptual framework (Figure 5), conveying its important influence on the lived experience and personal development of teenagers with DCD/dyspraxia. Participants expressed strong self-efficacy beliefs in three functional domains: activities of daily living, academic performance and social participation. These domains map closely to the three categories of occupational purpose in the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend and Craik 2007): self-care, productivity and leisure.

These similarities support the validity of the domains of function highlighted as important by teenagers with DCD/dyspraxia. Each of these functional domains is explored in turn.

Figure 7: Conceptual framework illustrating self-efficacy domains of concern to teenagers with DCD/dyspraxia



Efficacy for activities of daily living (ADL)

Adolescence is a time when young people typically develop the skills required to live independently, manage their lives, and take responsibility for themselves as adults (Blakemore and Mills 2013). By age 15, participants felt they had developed the skills necessary to perform basic self-care activities through repeated practice as part of their daily routine. However, they felt that it had taken more time and effort for them to master these activities compared to others because of their coordination difficulties, a perception that is supported by research demonstrating that children with DCD activate almost twice as many brain areas as control children when performing motor tasks (Zwicker et al. 2012). Missiuna et al (2006b) observed that young people with DCD were able to acquire functional motor skills such as dressing, albeit at a later age than their peers. However, while participants were able to perform these tasks independently, they were resigned to accepting a lower standard of performance, as illustrated by George's comment that he had to work hard to "*get stuff not like perfect, but do stuff like to a standard that's OK*". Accepting lower standards of performance increased the risk of dissatisfaction and disappointment when participants felt they hadn't reached their potential. This is of concern, as low levels of perceived self-efficacy are associated with an increased risk of depression (Gage and Polatajko 1994). Furthermore, setting lower performance goals had unanticipated consequences. Ian for example, was able to prepare

simple snacks but doubted his ability to prepare more complicated dishes such as a lasagne. Poor self-efficacy meant he avoided tackling more challenging meals, thus limiting opportunities to develop cooking competencies which could have implications for his future health and well-being.

Participants were motivated to work hard to master activities that they valued for personal or social reasons. Being able to tie an effective knot was especially important to Callum, who was prepared to practise hard so that he would look smart at church. Participants believed that 'over-preparation' was necessary to achieve an acceptable level of performance. Some members of the Reference Group also reflected that they also took an 'exceed to succeed' approach, investing extra time and effort to master specific skills, for example, intensively practising methods to cut and prepare vegetables. To others their efforts might seem obsessive, but participants and Reference Group members were motivated by these activities, believing in their ability to achieve them and persisting even when they encountered difficulties. Their experience supports Bandura's observation that people with a high sense of efficacy set themselves high goals, visualise positive scenarios and draw on their experience to modify their actions and reinforce factors that enabled their performance previously (Bandura 1994). The findings of this study however, extend Bandura's ideas, in that participants revealed it was impossible for them to achieve a level of competence to which they aspired in all activities. It was therefore necessary for them to be selective, investing time and effort in those activities that were personally meaningful and relevant, that were essential to get through the day without embarrassment, or for which they received positive feedback from others.

In some cases, participants had little choice about whether or not to persist with an activity, even if they doubted their ability to be successful, as illustrated by David's experience during compulsory food technology lessons at school. Despite David's anxiety about the risk (and his previous experience) of injury, his belief in his ability to handle sharp knives safely increased as a result of repeated practice with the support of an understanding teacher. David's experience supports Bandura's observation that *"those who persist in subjectively threatening activities that are in fact relatively safe will gain corrective experiences that reinforce their sense of efficacy"* (Bandura 1977), and suggests that teenagers with DCD/dyspraxia can develop the skills necessary for their future independence if provided with the right support and practice opportunities.

Participants' experience of having to dedicate more time and effort to master simple skills however, made them question their ability to master complex skills that they regarded as important for their future independence. Their concerns are supported by the findings of previous studies in which adults with poor coordination described learning complex motor skills, such as those required as part of a new job, as stressful and time-consuming (Missiuna et al. 2008a). Several participants

doubted their ability to learn to drive; their concerns are validated by research indicating that people with DCD have difficulty steering round bends and responding to hazards compared to matched controls (de Oliveira and Wann 2012). Like young adults interviewed by Missiuna et al (2008a), some participants coped by avoiding or withdrawing from complex motor activities that they felt were beyond their capabilities. While avoiding or trivialising such activities might preserve teenagers' self-esteem in the short term however, there may be unanticipated long term health, social, emotional and economic consequences when skills are not developed or activities not pursued during adolescence.

The findings indicate that teenagers with DCD/dyspraxia believe they have the capacity to successfully perform basic activities of daily living which they considered necessary for their independence and which were important to them for personal and social reasons, but worried about their ability to manage more complex activities associated with adulthood. Efficacy for learning and academic skills emerged as another significant domain of concern for participants and is explored in the next section.

Efficacy for learning and academic skills

Teenagers expressed strong efficacy beliefs about their academic abilities and their ability to reach their academic goals. While Billy and others considered themselves to be academically able, the findings reported in Chapter 5 indicate that participants lacked confidence in their ability to concentrate, manage distractions, and plan and organise their learning, believing these difficulties to be features of DCD/dyspraxia that were shared by others with the condition. Participants felt they had to work harder than others to manage their learning, and were frustrated when their efforts were not recognised by teachers and when the classroom environment hindered their performance. Receiving low marks for their work further reinforced their low self-efficacy and their motivation to continue. Finding that participants lacked efficacy for self-regulated learning is consistent with previous research indicating that children with DCD have fewer planning strategies than their typically developing peers (Kirby, Sugden and Edwards 2010) and may not know how to adjust a plan to make it more effective (Polatajko, Mandich and Macnab 2001). Research indicates that a student's belief in their efficacy for self-regulated learning affects their perceived efficacy for academic performance, which in turn influences the academic goals they set for themselves and therefore their academic achievement (Zimmerman, Bandura and Martinez-Pons 1992). Some teenagers with DCD/dyspraxia may, therefore, be at risk of academic disengagement and underachievement because their academic abilities are not recognised or supported.

While some participants had high expectations of themselves academically, most were negative about their handwriting abilities. Self-efficacy for handwriting was influenced by previous experience of struggling to read their own writing, teachers' negative comments about the presentation of their work, and by anxiety that they would not be able to manage increased expectations of written output as they grew older. Ian had tried to improve his handwriting but without success, reinforcing his belief that continued attempts to achieve a better outcome were hopeless. He resigned himself to accepting a lower standard of performance, but poorer marks and negative feedback from teachers reinforced his low academic efficacy. Ian's experience supports Bandura's theory that people who regard themselves as inefficacious attribute their failures to low ability (Bandura 1994). Feeling 'stupid' emerged as a strong theme in the current study, as reported in Chapter 5, and had a significant negative impact on participants' emotional well-being. The influence of social comparison on self-efficacy for handwriting is however called into doubt. Although participants rated their handwriting as poor compared to that of their peers, self-efficacy for academic skills was more strongly influenced by the grades participants achieved for their work. This finding supports Schunk's argument (Schunk 1984) that information gathered through social comparison exerts only a modest influence on academic self-efficacy, and that actual performance has a much stronger influence. For many participants, efficacy for handwriting operated separately from academic efficacy, as despite participants' poor handwriting, many maintained a high academic efficacy and considered themselves to be relatively intelligent. While participants did not judge their academic capabilities by their handwriting performance however, they were aware that others (including peers and teachers) did.

Participants expressed strong doubts about their efficacy for practical school subjects including design and technology. This was not unexpected, as poor motor coordination is a feature of DCD/dyspraxia (American Psychiatric Association 2013). Callum was frustrated that, as technology was often an area of strength for people with cognitive learning difficulties, the needs of people with DCD/dyspraxia were not recognised or supported in practical lessons. Lack of support and poor understanding of Callum's coordination difficulties, combined with the poor projects he produced, reinforced his poor self-efficacy for practical subjects. Participants' self-efficacy was also influenced by doubts about their ability to handle tools and equipment safely and effectively, and their anxiety was heightened by experience of previous injuries. According to Bandura's social learning theory (Bandura 1977), previous aversive experiences create expectations of repeated injury, leading to defensive and fearful behaviour. This was the case for David and Callum who had hurt themselves previously in woodwork classes and who disengaged physically or emotionally from these lessons. Bandura suggested that individuals' doubts about their capabilities were reinforced by physiological

reactions resulting from anxiety about performance outcomes and the perceived risk of harm. He identified anxiety reduction as a mediating mechanism for perceived efficacy, and suggested that reducing physiological arousal might improve performance by raising efficacy expectations (Bandura 1977). Therefore, as well as providing specialist equipment and tools to minimise the impact of coordination difficulties on teenagers' performance, reducing performance anxiety might offer an alternative intervention to enhance their performance of practical tasks.

Efficacy for social skills and participation

Friendships were important to all participants. For some however, efficacy for social skills had a negative impact on their confidence and motivation to engage in social activities. Some studies suggest that young people with DCD/dyspraxia are similar to others in their perceptions of social acceptance and competence (Watson and Knott 2006). Others however, report lower perceptions of social competence (Eggleston et al. 2012, Skinner and Piek 2001), a finding that was supported by the experience of some participants in this study. Ian doubted his ability to communicate effectively and was anxious that his comments might seem “*random*” and “*weird*” to others. He avoided interacting with people that he didn't know well, putting him at risk of social isolation. The risk of social isolation for children with DCD/dyspraxia has been highlighted previously (Dewey et al. 2002, Poulsen et al. 2007). Some participants anticipated rejection or teasing by peers and avoided situations where their difficulties might be exposed. Pajares (2006) similarly noted that young people who doubt their social skills envisage rejection or ridicule even before making a social contact, thus limiting opportunities for positive social interaction. Social avoidance could have long term implications for teenagers' psychosocial well-being. While participants felt accepted and a sense of belonging when with family members, close friends or peers with personal experience of additional needs, they doubted their social efficacy in other situations. Teenagers' efficacy for social skills therefore varied according to context in which interactions took place. The important influence of context on self-efficacy is explored later in this chapter.

Self-efficacy and DCD/dyspraxia

The findings of this study demonstrate that self-efficacy for activities of daily living, academic abilities and social skills were significant domains of concern for teenagers with DCD/dyspraxia. This is a new, significant finding as previous research into the self-efficacy of children with DCD/dyspraxia has focussed mainly on young people's efficacy for physical activity (Batey et al. 2014, Cairney et al. 2005a, Watson and Knott 2006). This is understandable, as a marked impairment of motor coordination is central to the diagnosis of DCD/dyspraxia (American Psychiatric Association 2013). Furthermore, understanding why young people with DCD/dyspraxia might avoid physical activities is important as there is growing evidence of increased risk of reduced physical activity among children

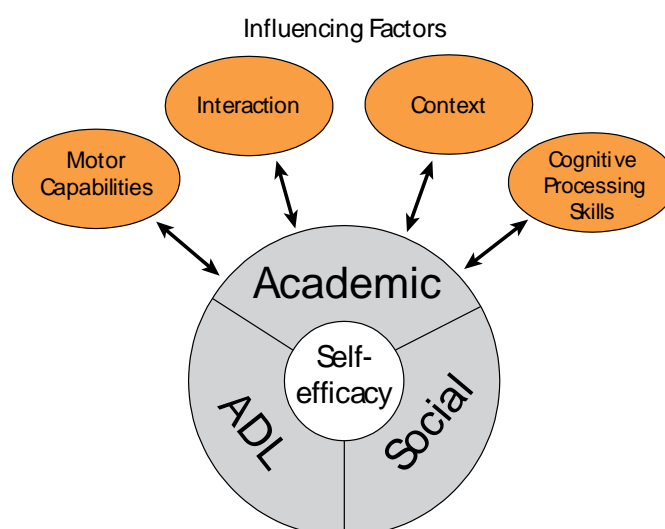
with DCD/dyspraxia (Cairney et al. 2005a, Cairney et al. 2010, Mandich, Polatajko and Rodger 2003, Poulsen and Ziviani 2004) which has long term implications for their health and well-being (Cairney et al. 2005b, Faught et al. 2005, Wu et al. 2010). However, focusing on efficacy for physical activity alone risks ignoring other important functional domains of concern.

Literature regarding the self-efficacy of people with DCD/dyspraxia is limited in both volume and scope. Understanding the impact of self-efficacy on participation in daily life activities is therefore important because it draws attention to the functional domains of concern to teenagers themselves. Furthermore, as perceptions of self-efficacy affect an individual's motivation, activity choices, persistence in the face of adversity and achievement goals (Bandura 1977, Bandura 1994), self-efficacy might impact on their future physical, economic, social and emotional well-being. The factors that were revealed to enhance or lower teenagers' perceived efficacy for everyday functional tasks are explored in the following section.

Factors influencing efficacy perceptions

The previous section examined the efficacy-beliefs of teenagers with DCD/dyspraxia in different domains of concern to them, and also demonstrated that teenagers could hold different views about their self-efficacy across different performance areas. This section reveals that participants' self-efficacy beliefs were shaped and challenged by a complex interaction of personal (physical and cognitive processing skills) and environmental factors (context and social interactions). Here I argue that understanding the factors that can enhance or lower teenagers' self-efficacy is important, as this may offer avenues for intervention to facilitate teenagers' successful participation in, and performance of, everyday activities at home, at school and in community settings. Figure 6 illustrates the personal and environmental factors that were revealed to influence teenagers' self-efficacy.

Figure 8: Conceptual framework illustrating personal and environmental factors that influence self-efficacy



Motor capabilities

Bandura argued that an individual's efficacy perceptions are strongly influenced by prior experience and accomplishments (Bandura 1986). As the performance of teenagers with DCD/dyspraxia is affected by their motor difficulties (American Psychiatric Association 2013), it is reasonable to assume that their self-efficacy will be influenced by their actual motor ability. Assessment of motor function is an important component of therapy practice with young people who may have DCD/dyspraxia (College of Occupational Therapists 2013a) and is supported by a number of standardised assessment tools, the properties of which are under frequent review (Crawford, Wilson and Dewey 2001, Larkin and Cermak 2002, Missiuna, Rivard and Bartlett 2006). Parents and professionals are however, often puzzled when people with similar motor ability participate in and perform activities at different levels. Self-efficacy may provide an explanation for this variation through its influence on teenagers' confidence. Eden for example, avoided sports because he didn't believe he could be successful. His experience supports Bandura's argument that self-efficacy is a mediator of performance (Bandura 2001) and that a person's perceptions of their capacity to carry out a set of actions will influence whether or not they choose to participate and the amount of effort they are prepared to invest in it (Bandura 1986, Bandura 1994). A consequence of Eden's avoidance of physical activities however, was that he missed opportunities to develop his motor skills, further reinforcing his poor efficacy for physical performance.

As has been demonstrated, merely possessing the motor capacity to perform a task does not mean that an individual will use those skills effectively. I therefore argue that even when a young person's motor assessment score places them above a test 'cut off' (a common criteria for determining

whether or not a person qualifies for therapy), teenagers who have low efficacy for motor activities may benefit from intervention to improve their performance and participation in physical activities. Teenagers may be unwilling to participate in physical activities because previous failure experiences cause them to doubt their abilities, or because they have observed others with similar motor abilities failing to succeed. They may also fear being ridiculed or teased by others (Fitzpatrick and Watkinson 2003). I contend that evaluating participants' efficacy for motor skills is an important but neglected area of practice for occupational therapists and other professionals, and that understanding the factors that influence an individual's efficacy for physical activities could indicate alternative interventions to enhance teenagers' performance, participation and satisfaction with their performance of physical activity.

Whilst poor motor coordination is a defining feature of DCD/dyspraxia, teenagers revealed additional difficulties that influenced their perceived efficacy for task performance. In the following section, the cognitive processing skills that influence teenagers' self-efficacy and performance of everyday activities are examined.

Cognitive processing abilities

As demonstrated in Chapter 5, the impact of cognitive processing difficulties on performance of everyday tasks emerged as a strong theme for most, although not all, participants in this study, affecting their motivation for, and performance of activities in both academic and non-academic settings. Participants shared characteristics such as poor organisational, planning and attention skills which they attributed to their diagnosis, supporting research by Rigoli et al (2012) establishing a link between motor coordination and poor executive function in adolescents with DCD. Further studies indicate that poor executive function may continue into adulthood (Kirby, Edwards and Sugden 2011, Tal-Saban et al. 2012). Participants doubted their ability to process information quickly, creating feelings of disorientation, anxiety and confusion when they were unable to execute a task as they or others expected. Their experience supports previous research identifying an association between DCD and working memory (Alloway, Rajendran and Archibald 2009, Chen et al. 2013). Participants were puzzled and frustrated by their inability to retain and act on instructions quickly, something that they observed others managing easily. Comparing their organisational and planning skills to others had a negative impact on teenagers' belief in their ability to tackle complex projects such as preparing a meal and helping with DIY tasks at home. Their experience supports the suggestion by White et al (2006) that social comparison with others who seem more able can reinforce a negative sense of efficacy in people with low self-esteem. Furthermore, teenagers were at risk of underachievement because they doubted their planning ability and set themselves lower

performance goals, thus reducing opportunities for the development of planning and organisation skills by limiting their activity choices.

Several participants revealed that problems with concentration and attention affected their ability to perform activities as they hoped, supporting the findings of a study linking poor attention with motor coordination difficulties (Zwicker et al. 2012). While some researchers suggest that the association between motor and attention difficulties can be explained by the overlap between DCD and attention deficit disorders (Kadesjo and Gillberg 1998, Kadesjo and Gillberg 2001, Kaplan et al. 1998, Watenberg et al. 2007), only one participant in this study, Eden, had a coexisting diagnosis of ADHD. Others however, felt that poor concentration and attention affected their ability to carry out activities successfully, particularly in busy environments. Billy for example, found it hard to ignore other people's conversations and tended to join in rather than focus on his activity. Billy's experience supports the findings of previous research indicating that young people with DCD have difficulty allocating attention appropriately and suppressing a response to an irrelevant stimulus (Mandich, Buckolz and Polatajko 2002). Poor attention and concentration influenced teenagers' efficacy perceptions because they found it hard to focus on tasks and were unable to achieve them to the expected standard. Moreover, negative performance outcomes further reinforced their sense of inadequacy.

Poor executive functioning is frequently described in the personal accounts of individuals with DCD/dyspraxia and has been reported in other qualitative studies (Kirby, Edwards and Sugden 2011, Missiuna et al. 2008a). These non-motor difficulties are not however, recognised in the criteria for the diagnosis of DCD (American Psychiatric Association 2013), although the existence of co-occurring difficulties with time management, planning and organisation is acknowledged in the Movement Matters description (Movement Matters UK 2013). Bandura (1994) identified cognitive processes as one of the four major psychological processes through which self-efficacy beliefs shape human behaviour, enabling a person to anticipate scenarios and plan actions to ensure their successful performance. According to Bandura's theory, self-efficacy beliefs are informed by individuals drawing on their knowledge and previous experience, and by testing and revising judgements about the potential results of their actions. The cognitive processing difficulties experienced by teenagers with DCD/dyspraxia suggest that they may have difficulty identifying the factors that enabled their performance and working out how to adjust their actions accordingly. This study therefore extends Bandura's social cognitive theory by demonstrating the impact of poor cognitive processing skills, as experienced by teenagers with DCD/dyspraxia, on self-efficacy and behaviour.

This section has so far discussed the personal factors (motor capabilities and cognitive processing skills) influencing the self-efficacy of teenagers with DCD/dyspraxia. I now move on to examine the environmental factors that influence teenagers' self-efficacy, specifically the physical context in which activities take place and their interactions with significant others.

Context

Teenagers' efficacy perceptions were influenced by the context in which activities took place, as illustrated by participants' experience of sporting and leisure activities. Teenagers' self-efficacy was lower in environments where their performance was judged against an expected performance standard by themselves and others. David for example, had been a motivated and enthusiastic member of a football team but withdrew when his performance measured poorly against normative standards (how many goals he saved) and as his inabilities became obvious to himself and others (Feltz and Magyar 2006). Festinger's theory of social comparison (Festinger 1954) suggests that individuals evaluate their abilities or opinions by comparing themselves to others. David's self-efficacy was lowered when he compared himself to better footballers. By contrast, George was enthusiastic about joining a cricket team for people with special needs where he felt there would be a good match between his abilities and those of his team mates. Rose et al (1999) argue that young people with DCD are disadvantaged because their physical performance is often compared to 'typical' standards against which they perform badly, whereas the performance of students with more obvious physical disabilities is typically judged against different standards. This argument is supported by George's experience as comparing his physical abilities to people of similar abilities enhanced his self-efficacy and motivation to play cricket.

Participants' self-efficacy was also enhanced by playing sport in situations where participation was valued more highly than performance, in contrast to environments where their performance was judged against formal standards. In informal contexts, participants felt that they wouldn't be unfairly judged by peers if their performance was inconsistent because the focus was on fun rather than competition. David and Billy for example were willing to engage in informal games of football with friends where performance standards were more flexible. Identifying leisure contexts that offer an appropriate match for teenagers' perceived performance capabilities is therefore likely to benefit teenagers' social and emotional well-being and encourage their motivation, as well as benefitting their long term health and physical fitness.

The enhancing or lowering effect of context on self-efficacy was also evident at school where participants felt more or less confident about their abilities in different learning environments. Efficacy for self-regulation of learning and academic performance was lowered when participants

were required to work in a distracting or unpredictable environment because it was hard for them to focus and concentrate. Furthermore, poor outcomes in some subjects, especially practical activities and those involving lots of handwriting resulted in lower grades which reinforced participant's poor efficacy for academic performance (Zimmerman and Cleary 2006). By contrast, participants' self-efficacy was enhanced in contexts that offered accommodations such as extra time or easy access to a laptop, or were less distracting. Some participants were willing to sit exams in a quiet room away from their peers, even though this highlighted their differences because they believed that the quiet, calm environment would enhance their performance. Participants' academic efficacy was further strengthened by their improved grades. Enabling environments also offered opportunities for participants to practice and develop adaptive behaviours and skills, which further enhanced their self-efficacy and therefore, maintained academic and career options for the future.

Bandura argued that efficacy perceptions were influenced by contextual factors as some situations required an individual to employ greater effort and skill to be successful and some carried a greater risk of negative consequences (Bandura 1977). This was perceived by teenagers to be the case in the technology workshop where the risk of injury was greater than in a standard classroom. Teenagers expressed relief that, as they got older, they had more opportunity to choose environments that enabled, rather than hindered their performance. Teachers were identified as an additional factor with the potential to enhance or lower teenagers' academic self-efficacy. The influence of interactions with teachers and significant others is examined in the next section.

Interactions

Interactions with others, including teachers, family members and peers, were seen to either enhance or lower the perceived efficacy of teenagers with DCD/dyspraxia. Bandura identified social persuasion as an important source of efficacy that could have either a positive or negative effect on people's belief in their ability to be successful (Bandura 1994). Teachers' responses were revealed to have a particular influence on participants' self-efficacy, supporting previous research by Schunk et al (1984) and Zimmerman and Cleary (2006). Negative comments about handwriting and the presentation of work made participants question their capabilities, especially when they were uncertain whether their poor performance should be attributed to factors associated with DCD/dyspraxia or a lack of intelligence. Negative feedback had a cumulative effect on perceived efficacy for academic skills, and meant participants were reluctant to put themselves forward in class. George and David for example, disengaged from lessons where they felt misunderstood and the teacher awarded low marks for their work, despite the effort they had invested. This supports previous research indicating that people give up trying when they lack self-efficacy and when they expect to be punished (Bandura 1977). By contrast, teachers and mentors who provided positive

feedback about participants' abilities enhanced their self-efficacy and encouraged them to believe that they could be successful at college and in their future careers, as illustrated by David's positive interactions with a student mentor. Teachers also enhanced participants' self-efficacy by providing feedback that linked their positive performance to successful strategy use. David for example, credited improvements in design and technology to the support he received from a teacher whose understanding of DCD/dyspraxia had improved following a visit by his mum. Billy's academic efficacy was enhanced by teachers who encouraged him to evaluate his performance and develop skills in essay planning and time management. The important influence of social persuasion on academic performance is further demonstrated by research indicating that students with higher perceived self-efficacy set high goals for themselves and achieved higher levels of academic performance compared to students of equal cognitive ability who were led to believe that they lacked such capabilities (Bouffard-Bouchard 1990).

Participants regarded their parents as generally supportive and understanding. However, at times parents' behaviour had unintended consequences for participants' self-efficacy. Some parents doubted participants' ability to handle equipment and kitchen tools safely and were reluctant to let them make snacks or assist with DIY projects. Over-protectiveness, even with the intention of protecting individuals from failure or injury, reinforced participants' doubts about their capabilities and limited opportunities for them to practice and master skills. Poor efficacy was further reinforced when parents asked younger siblings to help participants manage tasks, as illustrated by David's feeling of worthlessness at needing his sister's help to change the bedclothes. Similar findings were reported by Missiuna et al (2008a) who found that adults with DCD recalled feeling 'less able' because of their parents' frustration and disappointment when they struggled to master activities or spilled or broke things. By contrast, participants' self-efficacy was enhanced by parents who encouraged them to master activities such as tying shoe laces or handling a knife correctly. Parents were therefore revealed to have an important role in creating opportunities for teenagers to experience efficacious actions to enhance their sense of efficacy. Furthermore, enabling positive experiences may reduce the risk of affective disorders such as depression and anxiety, which are associated with low levels of self-efficacy in adolescents (Muris 2002). The impact of self-efficacy on coping and resilience is explored later in this chapter.

Interactions with peers influenced participants' efficacy for activities of daily living and academic skills, providing further support for the argument that social comparison is an important source of self-efficacy information (Schunk and Meece 2006). Bandura (1977, 1986) argued that 'similar others' offered the best basis for comparison and suggested that observing comparable people

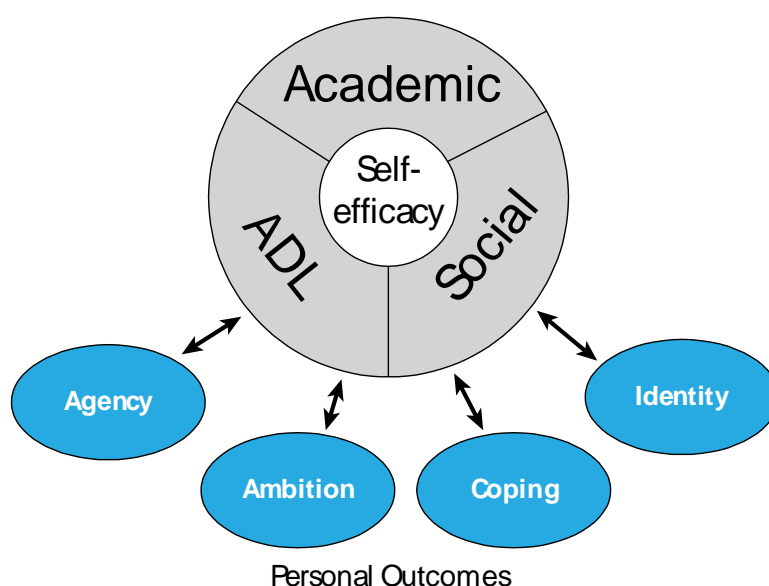
performing activities without adverse consequences would encourage a person to believe that their performance would improve if they increased their efforts. As discussed in Chapter 5 and experienced by other teenagers with 'hidden disabilities' as discussed in Chapter 6 however, participants' attempts to find an appropriate comparison group often proved unsatisfactory. George and David's efficacy for example, was neither raised nor lowered by comparisons with students with cerebral palsy or learning difficulties, because they did not regard these peers as similar enough to themselves. By contrast, George's belief in his ability to be successful was enhanced by comparison with the successful actor Daniel Radcliffe who also has dyspraxia. Social comparison was a good source of efficacy for George because Daniel Radcliffe was also a teenager and was articulate like himself, yet had similar problems with everyday tasks such as tying shoe laces. Having a positive role model was inspiring and encouraged George's belief in his ability to be successful.

Peers were an important source of social persuasion, providing feedback that influenced teenagers' beliefs about their performance capabilities. Participants' reactions to peers' negative comments about their inability to handle cutlery effectively, tie their shoe laces or produce legible handwriting demonstrate how this reinforced their sense of inadequacy. When participants anticipated being ridiculed they withdrew effort and excluded themselves from activities. By contrast, positive feedback about their accomplishments enhanced participants' sense of efficacy, as illustrated by the David's increase in confidence when his baking was appreciated by peers and family members. Participants' efficacy for social and other activities was further enhanced by peers who accepted them as individuals, including the personality 'quirks' that they associated with DCD/dyspraxia. Over the course of the study there was a sense that the pressure towards conformity lessened and that teenagers began to appreciate others' unique personality characteristics as they matured. Similar perceptions were reported by adults in the study by Missiuna et al (2008a) as discussed in Chapter 6. Feelings of acceptance enhanced teenagers' social efficacy and their sense of identity, a concept which is explored later in this chapter.

Efficacy-related personal outcomes

Previous sections in this chapter explored participants' self-efficacy for activities of daily living, social skills and academic performance, and the personal and environmental factors that influence participants' efficacy beliefs. In this section the personal outcomes of self-efficacy are examined. Personal outcomes include participants' sense of agency, ambition, coping behaviours and sense of identity. These outcomes may provide a useful framework for professionals working with teenagers who have DCD/dyspraxia to evaluate the impact of interventions and support on teenagers' performance and participation in daily life activities. These outcome domains are illustrated in Figure 9. In this section each domain is discussed in turn.

Figure 9: Conceptual framework illustrating the personal outcomes of self-efficacy



Agency

In the context of this study the term 'agency' refers to a person's capacity to exercise control over the nature and quality of their life (Bandura 2001). Teenagers engaged in a number of personal agency-related processes, for example making judgements about their capabilities, setting themselves goals, anticipating the likely outcome of different events and courses of action, evaluating contextual opportunities and barriers, and selecting and creating courses of action to achieve a desired outcome (Bandura 2001). Bandura (2001) identified three types of agency, all of which were evident in this study: direct personal agency (which is informed by efficacy beliefs as well as actual ability); proxy agency (that relies on others to act on one's behalf to achieve desired outcomes) and collective agency (which is exercised through social action and coordinated effort). Each agency type is explored in turn.

Participants expressed strong efficacy beliefs about their ability to exercise control over their lives. This was a particular concern for teenagers within the secondary school context where there was an expectation that they would take increasing responsibility for their learning when working with different teachers and completing and managing work outside the classroom (Zimmerman and Cleary 2006). George and Billy had a positive sense of agency; they believed that they had the capacity to perform academically and felt able to choose the learning approach that suited them best. David's efficacy for exercising control over his life was enhanced by access to equipment and accommodations that enabled him to achieve his academic goals, including the use of a laptop. However, like students with physical disabilities discussed in Chapter 6, his sense of efficacy and

personal agency was inhibited when he was prevented from using his laptop by teachers who didn't understand that this was an effective performance aid, and when he lacked confidence to explain how a laptop would help. Teenagers' personal agency and sense of efficacy was, therefore, inhibited when individuals felt unable to disclose their difficulties and explain how doing things differently would enable their school performance.

At school, participants did not always have direct control over the circumstances that affected their lives. Their ability to reach desired outcomes was therefore influenced by their efficacy for enlisting the help of adults who had access to resources or expertise, or who had influence to act on their behalf (Bandura 2001). David's accounts provide two examples that illustrate his efficacy for proxy agency. David needed the support of adults to facilitate access to resources and accommodations to enable him to reach his academic goals. His sense of agency was however, inhibited by a teacher who imposed equipment on him without taking into consideration his personal views, leaving him feeling disempowered and resentful. By contrast, his self-efficacy was enhanced by his involvement in termly review meetings where he was able to review his progress and explain what support he needed to enable him to reach his personal and academic goals. Involving David in analysing his performance, identifying methods for enhancing his performance and monitoring their success promoted David's agentic feelings of involvement and empowerment.

Teenagers were motivated to take responsibility for themselves as they moved through adolescence towards adulthood, but were frustrated when their efforts were hampered by people and situations. Loyal (2003) examined theories of agency proposed by the sociologist Giddens, who argued that people have causal powers as agentic beings to intervene and influence the course and outcome of life events. Teenagers' experience however, suggests that they did not always feel able to act to influence a situation, even if they wanted to. Their sense of agency was therefore inhibited by structural constraints which, as teenagers, they felt unable to influence. Teenagers' sense of agency was therefore influenced both by beliefs about their personal capabilities, and by their efficacy for influencing other people, processes and organisational structures.

The concept of collective agency, which refers to people's shared belief in their collective power to produce a desired outcome (Bandura 2001), offers interesting insight into the motivation of teenagers and members of the Reference Group to participate in the study. Teenagers and Reference Group members said they wanted to take part because they believed that doing so would raise awareness of DCD/dyspraxia and the issues of concern to teenagers in a way that was not possible for them to do as individuals. As described in Chapter 3, and illustrated in the film

http://www.youtube.com/watch?v=aJsW8NtUI_g, members of the Reference Group were very

motivated to help others, giving up their time and in some cases travelling long distances to attend meetings. Participants also valued the opportunity to work with others to raise awareness of DCD/dyspraxia as they felt it was difficult for them to improve the lives of other teenagers on their own. Understanding the process and benefits of collective agency for teenagers with DCD/dyspraxia offers the possibility of new ways of working to support teenagers with DCD/dyspraxia that will enable more effective use of scant statutory and voluntary resources.

Ambition

Adolescence is a time when individuals consider what they might do as a future career (Brown and Lent 2006). Participants' accounts indicate a clear link between their self-efficacy beliefs, the career options that they considered and their motivation for certain academic subjects. This finding is similar to that of adults with coordination difficulties (Missiuna et al. 2008a) for whom there was a relationship between self-efficacy and the type of career or work they chose to pursue. Some participants felt that certain practical careers were closed to them because of their coordination difficulties; others believed however, they had the potential to pursue careers that matched their academic, creative and linguistic capabilities. David had ambitions to be a maths teacher, while Billy wanted to be a lawyer and was motivated to put time and effort into his academic studies so that he could achieve his goal. Bandura (Bandura 1982, Bandura and Locke 2003) cautioned that a person's self-efficacy beliefs may limit occupational options because not pursuing activities could mean that they would not have the opportunity to develop certain skills. Eden was not motivated to participate in physical activities because proficiency in gross motor coordination would not help him to become a games designer. Previous research indicates that the higher the perceived efficacy for achieving educational requirements and occupational roles, the wider the career choices a person will consider and the better they will prepare themselves educationally for those roles (Bandura et al. 2001, Bandura and Locke 2003, Brown and Lent 2006, Zeldin and Pajares 2000). However, teenagers who doubt their academic efficacy are likely to reduce their academic aspirations, with potential unforeseen consequences for their future occupational and economic well-being.

Coping

The emotional impact of living with DCD/dyspraxia as a teenager emerged as a strong theme. It was also revealed that participants' belief in their ability to cope with difficult situations and the coping mechanisms that they employed varied according to the activity and context. Coping behaviour is defined as the process by which an individual evaluates what might and can be done in the face of a threat or challenge (Strecher et al. 1986). There are strong links between coping efficacy and resilience; resilience is defined as a person's ability to recover from setbacks, and is an emerging and important concept in the field of childhood disability (Margalit 2004, Morrison and Cosden 1997,

Patterson and Blum 1996). Many participants experienced a high level of anticipatory anxiety, worrying about things that might happen and feeling anxious when faced with tasks or activities that they had found challenging previously. This was the case for Billy, who described himself as being stressed and anxious all the time at 13 years of age. A study by Pratt and Hill (2011) had similar findings. Parents reported high levels of 'panic anxiety' among younger children with DCD when faced with new or challenging situations. Billy's coping efficacy improved and his anxiety lessened over the course of the study however, as he developed strategies to prevent problems from recurring and as he learned that the consequences of his actions were not always as negative as he had anticipated.

Participants varied in their efficacy for coping with feelings of frustration when unable to perform tasks to the standard that they and others expected. Ian doubted his ability to manage the frustration that built up over the course of the day and, like David and Adam, anticipated that the physical expression of his frustration would have serious negative consequences for him personally and socially. Ian's experience supports findings by Bandura et al (2003) indicating that people with poor coping efficacy are less able to resist the negative influence of peers. By contrast, spending time with peers who shared their interests and values enhanced participants' coping efficacy, as illustrated by Billy's relationship with a friend who helped him to calm down and remain in school when he was feeling upset and anxious. This finding is of note, as young people with DCD/dyspraxia are often grouped at school with children who have additional learning needs so that they can benefit from extra learning support. However, such organisational solutions may disadvantage teenagers with DCD/dyspraxia who are vulnerable to the negative influence of peers whose values and attitudes are different to their own, and who would benefit from observing the coping behaviours of more able students.

Teenagers' efficacy for managing stress and challenging environmental demands was an important determinant of their coping behaviour. Callum's fear of embarrassing himself at school meant he kept a low profile and avoided situations where his difficulties might be exposed. His experience supports Bandura's argument for coping efficacy as a regulator of avoidant behaviour (Bandura 1993). Avoidant behaviour however, limited Callum's opportunities to develop coping strategies, reinforcing his poor coping efficacy and making him less likely to put himself forward in certain contexts. Harry was also emotionally vulnerable; his self-efficacy for coping with stressful and threatening situations was severely impaired by the negative attitudes of some adults in authority, which had resulted in him having a 'nervous breakdown' two years previously. When first interviewed, Harry doubted his ability to effectively manage his emotional responses. By 15 years of

age however, he was more able to recognise symptoms of stress and anxiety and used strategies such as taking the dog for a walk to manage his emotions. Harry benefitted particularly from the support of specialist teachers, therapists and parents who helped to build his self-efficacy for regulating his emotions and provided an environment in which he was able to practice these skills.

Teenagers' coping efficacy was affected by the level of challenge imposed by the environment. While participants were able to employ coping strategies at home it was often hard for them to do so at school. As well as considering their coping strategies and the likelihood that a strategy would achieve the desired outcome therefore, participants had to evaluate whether or not they were able to apply a strategy effectively within a particular context. Understanding and enhancing an individual's coping efficacy is important as this has been found to reduce vulnerability to stress and depression and to strengthen resilience to adversity (Bandura 2001, 2003). Furthermore, efficacy for regulating emotional responses fosters pro-social behaviour, deters engagement in antisocial activities and enables teenagers to manage negative life events without falling into a cycle of hopelessness (Bandura 2006).

Identity

As discussed in Chapter 6, issues of identity among people with DCD/dyspraxia have received little previous attention in the literature (Lingam et al. 2014), but emerged as a strong theme in this study. Adolescence is an important time for identity formation, which develops through a process of social comparison (Festinger 1954) and through exploration of factors such as personal values, ethics and gender. Erikson argued that an optimal identity is experienced as a psychosocial sense of well-being; that is, a sense of knowing where one comes from, where one is going and feeling at home in one's body (Sokol 2009). The physical difficulties experienced by people with DCD/dyspraxia present an obvious challenge to the latter part of Erikson's identity concept because, as Billy explained, there were many times when everything about his body felt "*uncomfortable and wrong*". Furthermore, findings presented in Chapter 5 suggest that Billy's lack of coherence applied to more than just his physical body. Participants' sense of knowing where they came from was also compromised by poor understanding of their diagnosis, as they were confused about characteristics that might, or might not, be attributed to DCD/dyspraxia. Uncertainty about their diagnosis also affected participants' sense of where they might be going in the future.

Participants' sense of identity was shaped by their perceived competence in performing meaningful tasks, and by comparing their competencies to others and to social standards and expectations. Being able to deal effectively with tasks and challenges enhanced participants' view of themselves as competent. Billy's view of himself as academically able for example, was enhanced by his good

performance in exams. By contrast, being unable to use cutlery effectively made David feel “*like an idiot*”, challenging his view of himself as an intelligent and able person. Christiansen argued that professionals have a role in helping to build an individual’s sense of identity by enabling them to master tasks that are important to them and that form an essential part of their identity (Christiansen 1999). This is particularly relevant to occupational therapists who view occupation as the principal means through which identity is formed and expressed.

Festinger (1954) recognized the role of social comparison in the formation of identity. Through this process, individuals evaluate their opinions and abilities by testing them against others. Participants felt better off than people with severe or life-threatening conditions, but ‘less able’ than peers with no obvious difficulties. The ‘hidden’ nature of DCD/dyspraxia made it difficult for participants to identify a ‘similar’ group to whom they could compare themselves. Some participants felt they had a degree of ‘special needs’, but did not identify themselves as ‘disabled’, a view shared by teenagers with DCD/dyspraxia interviewed by Lingam et al (2014) and by adults interviewed by Missiuna et al (2008a). Indeed, most of the time participants considered themselves to be just like any other teenager, as their symptoms did not affect everything that they did, all of the time. For some, the realization that they had a specific learning difficulty, rather than a general learning difficulty, represented a turning point in terms of shaping their identity and self-esteem, an experience also shared by people with dyslexia (Glazzard 2010).

As discussed in Chapter 6, participants who were most accepting of DCD/dyspraxia as part of their identity had been knowingly living with their diagnosis for longer than other participants (Freya, Billy and George). By contrast, Callum’s disassociation from his diagnosis and sense that DCD/dyspraxia was something to be embarrassed about was reinforced by his parents who avoided discussing his diagnosis with him. Studies suggest that parents are anxious that ‘labelling’ a child with DCD/dyspraxia might lead to stigma and stereotyping (Addy and Dixon 1999, Missiuna et al. 2006b). However, I argue that the negative consequences of giving a child a label of DCD/dyspraxia are outweighed by the benefits of helping young people to integrate their diagnosis into their sense of identity before they reach adolescence, a time already associated physical, emotional, academic and social change.

Introducing the final components of the conceptual framework

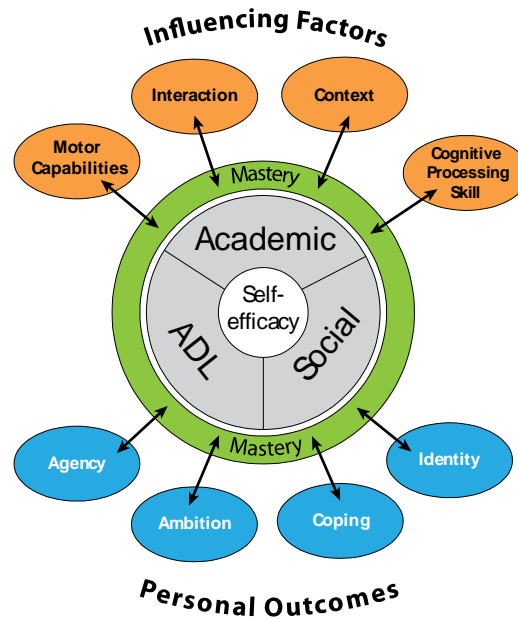
The previous section explored the factors that influence and are influenced by teenagers’ efficacy perceptions. Analysis highlighted two further themes that occurred across all concepts and which further illuminate the lived experience of teenagers with DCD/dyspraxia: mastery and time. Mastery was evident as both a source and a product of participants’ efficacy beliefs, while temporal factors

were shown to have a strong influence on participants' self-efficacy and performance of daily activities as they progressed through adolescence. The importance of mastery and temporal factors are illustrated in Figure 8 and are explored in the following section.

Mastery as both a source and product of self-efficacy

Mastery emerged as a common factor connecting all concepts within the framework as reflected by its position in Figure 8. Participants described mastery experiences (both positive and negative) in all performance areas; they also revealed the personal and contextual factors that determined whether or not their efforts to master a task were successful. While the findings support Bandura's theory (1977) that successfully mastering an activity enhanced efficacy whereas failing to master an activity lowered efficacy, it was revealed that participants needed more time, support and practice to master skills compared to others because of their physical and non-motor difficulties. It also took a strong sense of self-efficacy for participants to remain focused on a task when help was not easily accessed, or when faced with environmental or organisational barriers to their performance. Participants with a strong self-efficacy were however, prepared to invest time and effort to master a challenging goal that was personally meaningful. Moreover, like other teenagers with physical disabilities described in Chapter 6, when they did master a task or an activity, their confidence was boosted and they were motivated to continue, thereby developing more motor and non-motor competencies that allowed them to aim for higher, more challenging standards. Mastery experiences (positive and negative) therefore influenced participants' selection of activities and their motivation to persist or give up when faced with setbacks and challenges. These responses in turn, affected participants' sense of agency, ambition, their coping efficacy and their sense of identity. Mastery was therefore revealed as both a source and a product of self-efficacy, as demonstrated by its all-embracing position within the conceptual framework.

Figure 10: Conceptual framework illustrating mastery as both a source and product of self-efficacy



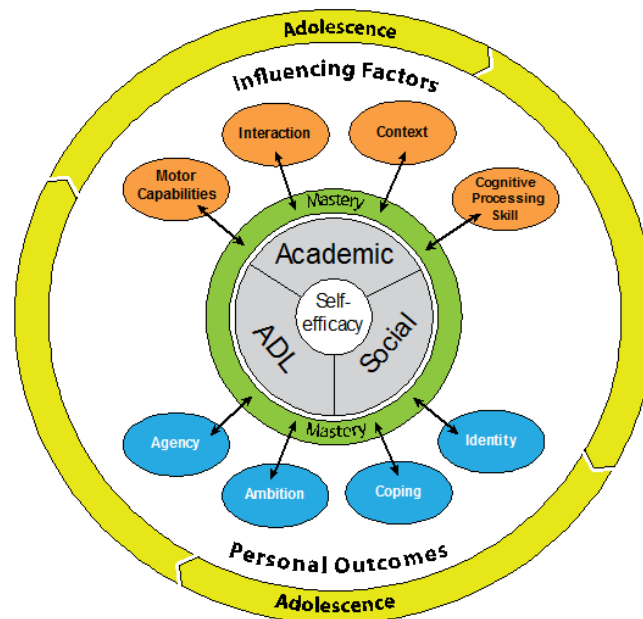
Temporal factors

A temporal aspect to the conceptual framework was revealed in participants' accounts indicating that their performance and satisfaction with their performance of everyday activities was influenced by changing competency demands and expectations over time. Time, specifically the adolescent life-stage, is therefore represented as a circle of arrows embracing all other elements within the conceptual framework (Figure 11). Temporal factors reflect the experience of young people with other disabilities and chronic illness as discussed in Chapter 6, and were apparent in both individual accounts and across the narratives of individuals who participated in multiple interviews during the study. The study structure offered a unique opportunity to evaluate and compare temporal aspects of self-efficacy for teenagers with DCD/dyspraxia as events occurred.

Temporal factors exerted a strong influence on self-efficacy as individuals made judgements about their capabilities based on previous experience and acted according to the anticipated likely outcome of their future actions (Bandura 1977, 1982, 2003). As demonstrated in Chapter 5, participants assessed whether investing time and effort in an activity was likely to result in a significant improvement to their performance, based on their previous experience. This evaluation influenced their choice of activities and their motivation to persist, as demonstrated by Ian's decision to revert to a printed style of writing because the effort of joining-up did not improve the quality or quantity of his written work. Previous experience of struggling to master skills that others managed easily, such as getting dressed, made participants question their ability to manage more complex tasks that are typical of adolescence, such as preparing a meal, and that they anticipated

having to manage in the future, for example, learning to drive. Thus, the findings demonstrate both immediate and long-term temporal aspects to self-efficacy for teenagers with DCD/dyspraxia.

Figure 11: Conceptual framework illustrating the complex interaction of factors affected the lived experience of teenagers with DCD/dyspraxia



Adolescence is a time of complex cognitive, physical and social changes which affect how individuals view their capabilities (Schunk and Meece 2006). The transition to secondary school represents a particular and major environmental change that challenges personal efficacy as students are expected to assume greater responsibility for their learning and to master new skills and activities (Bandura 2006, Zimmerman and Cleary 2006). Participants expressed concern at the growing gap between their motor capabilities and increased performance expectations over time. George for example, felt that his writing was similar to others at primary school, but was concerned about his written output at secondary school. Participants were increasingly challenged by the need to employ more complex executive skills such as time management, planning and organisation as they progressed through school. George's self-efficacy for learning was affected by the increased pace of work in years 10 and 11, and by the pressure to perform under exam conditions. Participants' concerns were similar to those experienced by adults with coordination difficulties reflecting on their adolescence (Fitzpatrick and Watkinson 2003, Missiuna et al. 2008a). While teenagers with a positive academic efficacy benefitted from greater flexibility to exercise control over their learning as they progressed through the school system, they also experienced a sense of relief when they

were able to 'drop' subjects that did not match their capability beliefs. There was, however, a sense of optimism that they would have more opportunity to use alternative tools and strategies in the future to enable their performance at college and university.

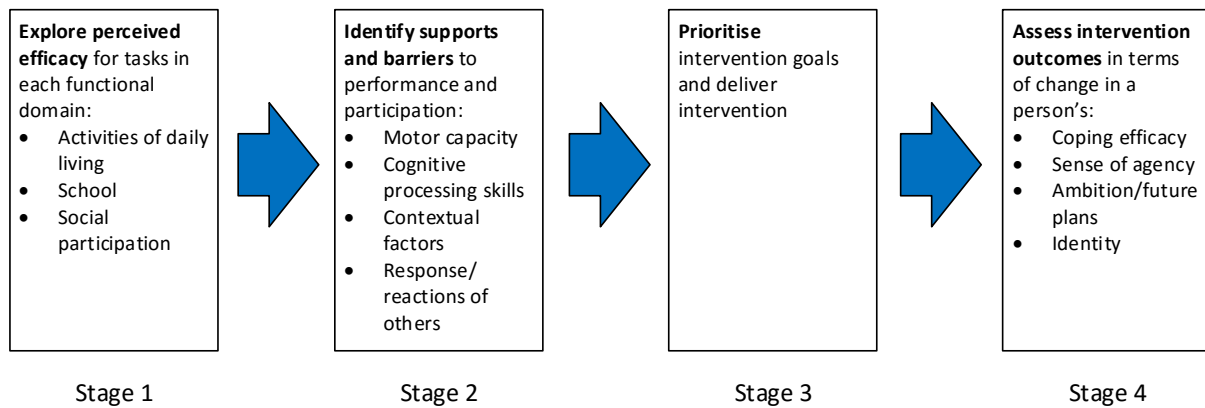
This study offered a unique opportunity to evaluate two participants' efficacy beliefs over two years. The narratives of one participant in particular, Billy, demonstrated the development of his coping efficacy over time. When first interviewed Billy was stressed and prone to somatic symptoms including aches, pains and nausea: similar findings were reported in young people with DCD by Dewey et al (2002) and Missiuna et al (2006b). Billy set himself very high academic standards and put himself under a lot of pressure to perform well in exams. Like other participants, he felt on a treadmill of assessment and struggled to manage his learning and worries. By 15 years of age however, Billy had learned to manage his stress and anxiety by adopting a variety of social, physical and creative strategies. Contrary to the suggestion made by Bandura (1994), Billy's experience suggests that teenagers who enter adolescence with a poor sense of efficacy do not necessarily transfer their anxieties and vulnerabilities to new situations. Billy's coping efficacy was enhanced by support from therapists who taught him stress management strategies, by his parents who provided opportunities for efficacy-enhancing experiences, and by teachers who provided positive feedback about his performance. Billy's emotional resilience, therefore, built through academic and coping mastery experiences during his early teenage years, and was reinforced by positive interactions with significant adults.

Temporal factors influenced participants' relationship with DCD/dyspraxia as they gained confidence and knowledge about their condition over time. There was a sense of moving from a position of feeling isolated by their difference, to an acceptance and embracing of their differences as part of their unique character. Participants were positive about having opportunities to revisit their diagnosis during adolescence and indeed, seemed to benefit from participation in this study as a way of developing their personal understanding of DCD/dyspraxia and what it meant for them now and in the future.

Developing an occupational therapy model of practice

Having developed a conceptual framework that illustrates the phenomenon of living with DCD/dyspraxia as a teenager, my thoughts turned to how this might be applied to my practice as an occupational therapist. The basis for an occupational therapy practice model, informed by the study findings and my experience as a clinician, is presented in Figure 12. In the following section I describe how the model might be implemented to enhance occupational therapy with teenagers with DCD/dyspraxia, a population currently neglected in clinical practice.

Figure 12: Practice model for occupational therapy with teenagers with DCD/dyspraxia



Stage 1

The occupational therapy process begins with an exploration of an individual's perceived efficacy for tasks that fall within the three functional domains of concern to teenagers: activities of daily living, academic tasks, and social participation. Asking teenagers to identify the home, school and social activities that they do well and those that they find hard places activity and participation at the centre of the process. Asking young people directly about their perceived strengths, difficulties and concerns is important, as the views of parents do not necessarily reflect those of the young person (Missiuna and Pollock 2000). While evidence suggests that many therapists use informal methods for measuring a person's confidence in their ability to perform activities as part of their client-centred approach (Poulsen et al. 2014), a valid and reliable tool for measuring teenagers' self-efficacy is required (Williams 2010). Such a tool is currently being developed by a team of Australian occupational therapy researchers (Poulsen et al. 2014).

Stage 2

The next stage requires therapists to identify the supports and barriers to teenagers' performance and participation in the activities and contexts that matter to them. Occupational therapists are skilled in assessing motor capacity (College of Occupational Therapists 2013b). However, the study also indicates the need to assess teenagers' cognitive processing skills. This is important as difficulties with attention, planning and time management affect teenagers' occupational performance outside the clinical setting where environmental factors and distractions have a significant impact on performance. The Assessment of Motor and Process Skills is one measure suitable for use by occupational therapists with teenagers, that captures the impact of a person's process and motor skills on their performance of personal and instrumental activities of daily living (Fisher 1995). The Evaluation of Social Interaction (Fisher and Griswold 2010) is also valid for use with teenagers, and shows promise as a tool that captures the quality of a person's social interaction in their natural contexts. One other measure, the School AMPS (Fisher et al. 2005), enables

assessment of the impact of motor and process skills and environmental factors on school performance; however, norm referenced data is currently only available for young people up to 12 years of age. Whilst this family of assessments enables occupational therapists to evaluate the personal and contextual supports and barriers to participation, their use is not widespread amongst paediatric occupational therapists in the UK (Payne and Howell 2005), because of the time and cost required to undertake training to administer the tools and interpret the results. There is therefore a need for additional valid and reliable, clinically relevant tools that evaluate the impact of contextual factors, as well as personal factors, on teenagers' occupational performance.

Stage 3

Having identified the performance areas and activities that present a challenge to teenagers in their daily lives, and the personal and contextual factors that enhance or hinder their performance, occupational therapists next agree goals for intervention with the young person. Taking into account teenagers' perceptions of their ability to perform tasks during the goal-setting process will enable therapists to identify therapy goals that an individual feels they can attain, thus increasing their motivation to work towards that goal and increasing the likelihood of a successful outcome (Gage and Polatajko 1994).

Occupational therapists have access to a variety of interventions suitable for use with teenagers with DCD/dyspraxia. Occupational therapists are skilled in breaking down activities into parts which are easily mastered, and identifying appropriate and acceptable supports and strategies to enhance teenagers' task performance. The findings suggest however, that occupational therapists should broaden their practice to consider ways of enhancing teenagers' self-efficacy for important life skills such as use of public transport and budgeting. These activities were identified as being of particular importance to teenagers with DCD/dyspraxia as a means of facilitating their future independence.

Enabling teenagers with DCD/dyspraxia to better manage their anxiety is another relevant but neglected area of practice. Bandura (1977) recognised that the physiological symptoms of anxiety affect an individuals' belief in their ability to successfully perform an activity. Occupational therapists are skilled in anxiety management, but this is rarely considered as an intervention approach for people living with DCD/dyspraxia. Helping teenagers to manage anxiety may enhance their efficacy for coping with challenging situations and, therefore, their occupational performance at school, in the community and in other social settings.

Stage 4

Stage 4 of the practice model involves the evaluation of intervention outcomes. The findings suggest that intervention outcomes could be measured not only by changes in task performance, but also by

changes in an individual's sense of agency (the degree to which they feel they have influence over the factors that affect their occupational performance), emotional resilience (coping efficacy), belief in their ability to be successful in their chosen career, and by an individual's sense of identity. Demonstrating changes in these domains would enable occupational therapists to show the impact of interventions both for individuals and for teenagers with DCD/dyspraxia who, as a population, are currently neglected in both clinical practice and research.

Chapter Summary

This chapter developed the findings presented in Chapter 5 and themes drawn from the wider literature examined in Chapter 6, drawing these together into a conceptual framework that illustrates the complex interaction of factors representing the lived experience of teenagers with DCD/dyspraxia. Participants' accounts were situated within a wider theoretical context, drawing on the extant literature to shed light on what was found. The process of IPA therefore moved the study findings into new, exciting and unexpected territory, offering insights that illuminate the lived experience of teenagers with DCD/dyspraxia. The conceptual framework provides coherence to the study by offering a way of thinking about the functional domains of concern to teenagers, the personal and environmental factors that influence teenagers' performance of everyday activities and their impact on teenagers' personal development and sense of identity as they make the transition towards adulthood. It also forms the basis of a new practice model for occupational therapists to guide practice with teenagers with DCD/dyspraxia.

In the next chapter I appraise the methodology used, evaluating aspects of the process to determine the study strengths and limitations. Particular consideration is given to the impact of user involvement as this is offered as a unique and novel contribution to the practice of interpretative phenomenological analysis.

Chapter 8

Methodological review and reflections

Chapter 8: Methodological review and reflections

In this chapter I evaluate the use of interpretative phenomenological analysis as a methodological framework for this study, making transparent the methodological choices made and my role as researcher in taking those decisions. Particular attention is given to the involvement of the Research Reference Group as 'user involvement' is offered as a particular and novel contribution to the practice of IPA.

Ethics

My experience of conducting this study highlights the importance of considering ethical issues at all stages of the study and not just at the outset when issues of informed consent and confidentiality are most apparent. The challenge of maintaining a commitment to the ideographic approach of IPA whilst ensuring the anonymity of participants when writing papers for publication was raised during recent discussions on the IPA Research Interest Group web forum (<https://groups.yahoo.com/neo/groups/IPANALYSIS/info>). I have attempted to manage this tension by providing sufficient information to allow the reader to interpret the findings in relation to their own experience, for example providing information about participants' ethnicity and background, but have used pseudonyms and removed reference to names and places so that participants cannot be identified.

Sample

IPA has been criticised for having small samples, limiting the extent to which findings can be generalised (Erskine 2012). However, the ideographic nature of analysis in IPA means that sample sizes are necessarily small to enable the intensive analysis of individual accounts (Smith, Flowers and Larkin 2009). This study involved nine participants and a total of 16 interviews, generating a considerable amount of rich data suitable for analysis. The number of participants is a little higher than that suggested by Smith and Eatough (2006) as typical for postgraduate IPA studies. While Collins and Nicolson (2002) argue that analysis of large data sets may reduce the depth of analysis, this study took place over several years, allowing time for the intensive analysis required and the building of themes and patterns over time.

The rationale for choosing purposive sampling, a relevant recruitment strategy for an IPA study (Smith, Flowers and Larkin 2009), was provided in Chapter 4. As occupational therapists are the health professional most likely to be involved with children with DCD/dyspraxia (Forsyth et al. 2008), I could have recruited participants through my occupational therapy networks. Navigating the required ethical procedures would, however, have added to study timescales and, as many occupational therapy services prioritise younger children with DCD/dyspraxia (College of

Occupational Therapists and National Association of Paediatric Occupational Therapists 2003), this may not have been effective in recruiting adolescent participants. As teenagers are a 'hard to reach' population I chose to recruit participants via the Dyspraxia Foundation. This enabled me to access teenagers with experience of the phenomenon and who were geographically diverse and varied in their personal, social, academic and leisure experiences. This recruitment strategy did not however, allow me to access teenagers who had a diagnosis of DCD/dyspraxia but who had rejected the label, or those who were living with DCD/dyspraxia but who had not been diagnosed. Different views and experiences may have been found in these populations (Portway and Johnson 2005). Despite this limitation, I contend that the findings of this study are valuable in their own right as they shed light on the lived experience of a group of teenagers with DCD/dyspraxia whose experience has not previously been explored.

A limitation of the recruitment strategy was that I did not have access to participants' medical or therapy records and had to rely on information provided by parents to confirm that teenagers met the inclusion criteria. Some parents provided a copy of medical or therapy reports; however it was still a surprise to find that one participant, Adam had received a head injury that might have accounted for some of his symptoms and experiences. I decided to include his data in the analysis as he had received a diagnosis of dyspraxia before the head injury, although I chose not to analyse passages from this transcript that referred to headaches and fatigue as I was not confident that these symptoms were attributable to DCD/dyspraxia. Including previous experience of a head injury, another major trauma, or life event that might have adversely affected teenagers' development, as exclusion criteria is recommended for future studies.

As discussed in Chapter 4, participants in IPA research are sampled to form a homogenous group who can offer insight into the phenomenon from a perspective of common experience. All participants met the study inclusion criteria and had previously been diagnosed with DCD/dyspraxia. However, no attempt was made to assess or control for the severity of participants' motor difficulties. While this might be regarded as a weakness of the study, Bandura argues that people's performance of activities is based more on what they believe, than on what is objectively true (Bandura 2012). This is because people's perceptions of their abilities determine what they do with the knowledge and skills that they have. Future studies might investigate the link between actual motor (and non-motor) ability as measured by a standardised test, for example the Movement ABC, (Henderson and Sugden 2007), perceived self-efficacy for performance of significant daily tasks/occupations, and actual performance of those tasks in context, using a tool such as the Assessment of Motor and Process Skills (Fisher 1995). As discussed in Chapter 2, research suggests

that young people with more severe coordination problems might have poorer social, emotional and academic outcomes. What this study demonstrates however, is that teenagers with DCD/dyspraxia have continuing difficulties in a range of functional domains, even if their motor problems lessen over time.

The gender imbalance in the sample population is a limitation of this study, as Freya's interview was only one of 16 conducted. I attempted to recruit more girls for the third round of interviews by advertising specifically for female participants, but unfortunately this strategy was unsuccessful. Prevalence studies suggest that the gender ratio for boys:girls with DCD/dyspraxia is around 2:1 (Lingam et al. 2009). However, my clinical experience and the personal experience of members of the Reference Group, suggests that girls are typically older when diagnosed. Thus, the population of teenage girls with a known diagnosis of DCD/dyspraxia is likely to be smaller than that of teenage boys. Furthermore, teenage girls may have been diagnosed only recently, which might affect their willingness to discuss their experience. The findings of this study are, therefore, presented with the caution that they may not represent the experience of teenage girls with DCD/dyspraxia.

Data gathering

The credibility and validity of this study was enhanced by gathering contemporaneous information from teenage participants. This is important, as subsequent experience inevitably colours a person's reflections on thoughts, feelings and emotions experienced in the past. A feature of data collection in IPA is its reliance on the "*representational validity of language*" (Willig 2001), meaning that researcher only has access to how the participant describes their experience, not to the actual experience itself. Semi-structured interviews were chosen as the data collection method for reasons outlined in Chapter 4. While teenagers with verbal dyspraxia or English as a second language were not specifically excluded from the study, the fact that data collection was via semi-structured interview may have deterred some young people from participating if they doubted their verbal competence.

During interview, some participants provided short answers, needing prompts and encouragement to expand their responses. These probes might have introduced bias by leading the participant to consider matters that were of interest to me, rather than of concern to them. As is demonstrated in the extract below however, participants did not pursue an issue that I introduced if it was not personally meaningful. In this exchange I hoped to find out about Harry's experience of exams:

Researcher: Do you think the way that you deal with exams and assessments is different or similar to other people?

Harry: I don't know. I don't know how other people deal with the exams.

Researcher: Can you explain what happened when you did your Maths exam?

Harry: It's hard to explain, I can't remember now, yeah there was, we were in the Hall.

Researcher: Okay, and you don't normally have lessons in the Hall?

Harry: No. All of us went into the Hall and then we did our exam. Then we went out.

Harry struggled to answer questions which I hoped would help me to understand his feelings about exams. It's possible that a lack of insight into his emotions made it hard for Harry to make sense of his feelings and to compare himself to others. Alternatively, Harry might just have felt uncomfortable talking about his feelings in depth. Either way, this line of enquiry did not enable me to explore the essence of the meaning of exams for Harry. This example suggests that the reliance on a person's ability to produce articulate descriptions about complex phenomena such as the experience of being a teenager with DCD/dyspraxia might be a limitation of IPA. Huws and Jones (2008) however, argue that the role of the researcher in interpreting the mental and emotional states of people whose experiences might otherwise be neglected, is a strength of the approach. This highlights the importance of involving a range of participants in IPA studies to ensure that the essence of the phenomenon under investigation is appropriately examined, rather than specifying a particular number of participants included in a sample. This may be particularly important for studies involving young people, as some transcripts may offer richer data for analysis than others.

Credibility and trustworthiness of findings

The principle of transparency is an important aspect of quality in qualitative research (Smith, Flowers and Larkin 2009, Yardley 2000), and refers to how clearly the stages of the research process are described. In Chapter 4 I provide an audit trail of decisions and processes, enabling the reader to follow the chain of events and evidence, from data collection to the development of the conceptual framework, to demonstrate that the conclusions reached are credible.

IPA has been criticised for introducing subjectivity, as the process of interpretation may lead the IPA researcher to create an account based on his or her background that is legitimate, but at the same time different to that of the participant (Cronin-Davis, Butler and Mayers 2009). The validity and credibility of findings is further challenged by the argument that researchers may differ in their interpretation of findings and the prioritization of emergent themes (Pringle et al. 2011), making it hard to "*verify their truth statements*" (Lyons 2011). I make no claim that the findings presented in Chapter 5 represent the only possible interpretation of participants' experiences. However, by

providing information about my personal and professional background, the involvement of the Reference Group, and by explaining the process by which I reflected on and considered the relationship between myself, the Reference Group and the data, I have made transparent the influence of my personal role on the analytical process and findings, allowing the reader to make up his or her own mind as to the credibility of the interpretation.

Credibility of analysis in qualitative studies can be enhanced by involving others in the analysis of individual transcripts. Doing so can highlight different interpretations, enabling alternative perceptions to be considered and leading to a far richer level of interpretation (Martindale, Chambers and Thompson 2009). Although I was ultimately responsible for carrying out the analysis, I involved others in the analytical process by sharing two transcripts with two colleagues experienced in IPA and qualitative research. Our discussions and the sharing of interpretations enhanced my analysis by enabling me to consider different perspectives. These ideas were further developed during discussions with my supervisory team. The Reference Group also played a significant role in the analytical process. My naïve plan in the early stages of this study was to take my analysis to the Reference Group for ‘validation’. However, as I learned more about IPA through reading and reflection, I realised that the concept of having findings ‘validated’ by others was not consistent with IPA and that it would be inappropriate for another person to ‘validate’ my interpretations. The role of the Reference Group therefore shifted, so that they played a greater role in the analytical process, enhancing the validity and credibility of the study by adding an insider’s perspective. The themes and discussion presented in Chapters 5, 6 and 7 therefore represent my interpretation of the experience of living with DCD/dyspraxia as a teenager, which was informed by discussion, reflection and review with others as described above.

Transferability

In Chapter 1 I described my personal and professional background and their influence on the study. Chapter 2 summarised claims made in the extant literature, while in Chapter 4 I provided information about the study participants and the context in which the study was undertaken. I have therefore, provided a rich, transparent and contextualized analysis of participants’ accounts (Smith, Flowers and Larkin 2009), allowing the reader to evaluate the study’s transferability to their own situation and context. I do not make claims for generalisation of the study findings; however by identifying commonalities across accounts I have offered insights which, as demonstrated in Chapter 7, have the potential to influence and contribute to the development of theory. The responsibility for determining whether the findings can be transferred elsewhere, however, rests with the reader who judges whether the research context and assumptions that underpin the study are relevant or similar to his or her own, based on the information that I have provided.

Evaluation of user involvement in the study

In this section I evaluate the role of the Reference Group, and their influence on the study. As demonstrated in Chapter 3, user involvement in IPA is unusual and presents both challenges and opportunities. Here I evaluate the level of involvement of the Reference Group and factors that influenced this, the challenges associated with involving users in the study, and the impact of user involvement on the research and on members themselves.

Level of involvement

Members of the Reference Group were involved as collaborators in this study (INVOLVE 2012a). This level of user involvement was determined by a number of factors, each of which will be explored in turn. While the research question could have been addressed by a user-led study, it is part of the academic requirement for a PhD that I demonstrate my skills and competence as a researcher. In order to achieve this I was required to take on the role of lead researcher and, as my interest in the research area is professional rather than personal, the study was not therefore user-led. University procedures also limited the level of user involvement as I was required to complete the ethical approval process before involving service users in the study. The experience I have gained, however, will enable me to develop future research proposals that involve users to a greater extent throughout the research process.

Ethical issues also influenced the level of user involvement. While members of the Reference Group could have undertaken the interviews, they would have required DBS clearance because participants were all under-18. No system for organising DBS checks through the university exists for people who are not students or members of staff and, if arrangements could have been made through the Dyspraxia Foundation, this would have added to project timescales and incurred costs for which there was no budget. INVOLVE (2010) recommend training and support is provided for user-researchers to ensure the rigour of the research and that user involvement is ethical and meaningful rather than tokenistic. A number of training packages to provide service users with the skills needed to participate in or lead research projects have been developed (INVOLVE 2010). However, the time commitment for such training ranges from 16 sessions to one week. Funding was not available to facilitate this, and the part-time nature of my studies limited the time I had available to provide the necessary support and mentoring to ensure the well-being of inexperienced user-researchers (Coad 2012).

The duration of the study was another factor influencing the level of user involvement. Guidelines developed by the PEAR group identify young people's motivation and changing circumstances as challenges to the involvement of young people in research over an extended period of time

(National Children's Bureau 2010). I was concerned that people would be deterred from joining the Reference Group if required to commit to involvement for the full three years. I therefore asked that individuals committed to attend a minimum of two sessions. In practice, attendance varied from 1-6 sessions, with only 1 person attending all six meetings. Many members of the group were students or in employment, so meetings were arranged on a Saturday, but attendance was affected by social commitments and study pressures. Maintaining communication with group members over the course of the three year project was also challenging. I lost contact with some potential group members when their emails bounced back or phone numbers were unobtainable. Keeping up to date contact details was difficult as there were often several months between contacts and group meetings. One member of the group also went on maternity leave during the project, but was pleased to hear about the project progress on her return.

Challenges of user involvement in this research project

This section describes the practical and ethical challenges associated with involvement of older teenagers/young adults with DCD/dyspraxia as co-researchers in the study. Some challenges relate to the specific profile of people with DCD/dyspraxia, while others were more practical. A particular ethical challenge involved managing the sensitivity of the data discussed during the analytical process, and the impact of these discussions on Reference Group members. Each of these challenges is considered in turn.

Meeting the needs of the user group

INVOLVE highlight the importance of considering the needs of service users when involving them in research (INVOLVE 2012c), and I encountered a few challenges specific to people with DCD/dyspraxia during the research process. Participation in the very first Reference Group meeting was affected by the cold and icy weather. While winter weather is challenging for anyone using public transport, it is particularly challenging for people with DCD/dyspraxia who have poor balance and coordination. As one person said in an email apologising for her absence *"I normally can't even get down to the station on my own in the ice!"* Another challenge that I had to address was members' poor organisational skills. Several people had double-booked themselves and weren't able to attend meetings at short notice, while one turned up as the meeting finished rather than when it started. I subsequently decided to text group members a couple of days before the meeting to remind them of the details. In some cases I also emailed their parents a reminder about the meeting if I had their contact details (for example if they had made the initial contact with me on behalf of their son/daughter). Although this felt a little paternalistic, I reconciled my actions with the knowledge that group members were so passionate about the project that they would be very upset if they missed a meeting unnecessarily.

Two young adults with DCD/dyspraxia expressed an interest in joining the Reference Group, but decided not to participate, citing difficulties talking in a group setting. DCD/dyspraxia can affect a person's ability to communicate within a group in several ways. People with verbal dyspraxia have difficulty making and coordinating the precise movements required for the production of clear speech, so that their speech is unclear and even unintelligible. For others, delays in processing information can make it difficult to follow a conversation and formulate appropriate and timely responses. As demonstrated by Ian's experience, poor processing speed can affect a person's confidence when talking in an unfamiliar group setting, and may have deterred some people from participating in the project. While face-to-face meetings are a quick way of generating a group discussion and gathering feedback, future projects might consider introducing a web-based discussion forum as an opportunity for involving people with communication difficulties in DCD research.

Practical challenges

Several people travelled some distance to the group meetings, for example from Surrey, Hertfordshire and West Sussex, using a combination of public and private transport. Those living in the West Midlands attended more meetings in total than those living further away, which suggests that travel distance did affect group membership. I offered to meet all reasonable travel costs, but not all group members chose to make an expenses claim, indicating their commitment to the study. When one group member was unable to attend a meeting at short notice because of traffic problems, I arranged to speak to her after the meeting by telephone. She was therefore able to have some input into the development of interview questions and felt she had contributed to the project.

I was fortunate to find a meeting room in a community clinic close to a mainline train station and local bus services for Reference Group meetings. We had exclusive use of the building and kitchen facilities, and used a room that was well lit with comfortable chairs. It was important to find an easily accessible meeting venue that was comfortable but with a professional feel, to reflect the value I placed on the involvement of Reference Group members.

Ethical challenges

Blake et al (2007) highlighted potential issues of confidentiality in IPA research in which user-researchers were exposed to sensitive and personal information about each other and participants. They recommended that processes and ground rules for ensuring confidentiality should be established from the start of the project. I was aware that members might share personal information about their own experiences during the meetings. This was mentioned in the Reference Group Information leaflet, and the need to ensure confidentiality and privacy was reiterated at the start of each meeting. This was appreciated by one group member who commented:

Bryn: The whole difficult life thing doesn't lead you to be generally trusting so you saying "This goes no further, it stops here" is a useful thing to say.

Another group member felt reassured by the group's empathy and was prepared to share experiences for the benefit of the research:

Imogen: I feel OK here about talking about my problems because we've all got the same problem really. I don't really like talking much to other people about it.

Hearing quotes from participants that indicated the social and emotional impact of living with DCD/dyspraxia was an emotional experience for some members of the Reference Group, a concern highlighted by Staley and Minogue (2006). It caused one member to reflect on her own unhappy experience at secondary school:

Dawn: School was very sad for me. It's making me feel a bit sad now talking about it.

I responded by checking that Dawn was OK to continue, and other members of the group supported her by contributing their own experiences of school life. After the meeting I contacted Dawn to check that she was OK. Her response indicated that she felt it was worth sharing her difficult experiences because doing so could make a difference to other young people with DCD/dyspraxia:

Dawn: I was fine and thanks for your concern. I haven't spoken about school days for such a long time and I guess had put the pain in a box somewhere. I really do not feel exploited in anyway, in fact I think it's healthy for me. I am a rather emotional person anyway and cry very easily. As I said in the meeting I would never want a child to experience the difficult times I had largely down to my dyspraxia being dealt with in a not very helpful manner so I am fine with it.

At each Reference Group meeting I provided information about other organisations (DANDA and the Dyspraxia Foundation helpline) that group members could contact for further support if they so wished.

Impact of user involvement in the project

In this section I evaluate the impact of user involvement on the research and the value that their involvement added to the study. User involvement influenced the study design and conduct, data collection process, data analysis, and the generation of knowledge. The impact of the Reference Group on the dissemination of findings is also examined.

Impact on project design and conduct

The impact of the Reference Group on the design and conduct of the study was limited by project timescales, academic processes and the ethical approval system. Members of the group did however, confirm the appropriateness of the proposed research design, as this extract illustrates:

Researcher: I'm going to be interviewing them probably in their own homes and I've asked that parents aren't present. Is that right?

Colin: Yeah, that's sensible

Andrew: Yeah, that's it, yeah

Bryn: Cos there's things we will not say when our parents are present.

Impact on data collection

The Reference Group played a key role in development of the interview schedule. Being part of a group discussion helped members to recall the events and situations that were important to them at different ages. During one meeting for example, the group discussed how dyspraxia affected their experience of being offered special support at school. I listened to the conversation and summarised what I felt was a key theme that could be developed into an interview question:

Researcher: So I could ask these teenagers "Are you having specialist support at school? How does that make you feel?" Some people will say "I don't like it" or "these bits are good but I'm not so sure about these bits" and other people will say "I couldn't function without it". So that would be a really good question.

Involvement of the Reference Group enhanced the collection of relevant and useful data by helping me to frame questions and use words/phrases that the group felt would elicit the information we were looking for. We agreed that it would be useful to explore the development of participants' "dyspraxic identity" over time. In the second round of interviews I asked "How do you feel about having dyspraxia now?" but for the final round of interviews the Reference Group suggested asking "How comfortable are you with your diagnosis now?" with the following additional prompts:

- Has how you feel about dyspraxia changed as you've got older?
- Has anything happened to change your feelings about having dyspraxia?

Use of the phrase "how comfortable are you?" would, we hoped, encourage a more reflective response from participants, while the additional prompts would encourage them to provide examples of events or circumstances that had changed their views. Thus, the wording of the question would encourage participants to "think out loud" about how they made sense of their

experiences, providing information suitable for interpretative analysis (Smith, Flowers and Larkin 2009).

Impact on data analysis and generation of knowledge

Involvement of the Reference Group brought different knowledge and an insiders' perspective to the analytical process. The focus of qualitative research (and IPA in particular) is not about finding one objective truth, but about articulating "one version of the truth" about a human phenomenon. Involving the Reference Group added their perspective to the analysis, allowing the phenomenon (being a teenager with DCD/dyspraxia) to be understood in greater depth and detail. To illustrate how the Reference Group influenced data analysis, extracts from a discussion about support offered to participants at school is presented. This was triggered by the following quote taken from the first round of interviews:

Quote: *She gave me this sticky thing that I put my woodwork on like, and everyone will look at me cos it's actually like this thing. And she gave me like these scissors and it was just like she knew what's best, and I didn't want those because they were really embarrassing and they were really noticeable. It's the sort of things like that I don't want to use like, does that make sense? Like the special people use.*

My response to this quote focused on the meaning of the physical presence of the specialist equipment for the participant. He seemed almost horrified by it ("It was actually like **this thing**") (emphasis added) and was embarrassed that it would draw attention to him, alienating him from his peers and marking him out as someone who was "special" and different. The Reference Group added that while the equipment might solve the participant's practical difficulties, the social and emotional impact might outweigh the benefits:

Dawn: At that age I was getting bullied which was through being different and not really having great social skills anyway. And that would have just added to it. It was just, it would bring more attention to me when sometimes you just want to blend in the background.

The group recognised the person's knowledge about his own condition and his frustration that he wasn't consulted about approaches being implemented at school. They also identified with his powerlessness and dependence on adults to allow him to access to equipment and strategies that would support his performance and participation:

Bryn: The kid knows what they need. I knew what I needed, every other dyspraxic I know knows what they need. And whether they get it or not is dependent on the teacher. If the teacher gives them what they know they need, they will get through.

The Reference Group therefore helped me to gain a deeper understanding of the impact of the lack of consultation between teachers and teenagers with DCD/dyspraxia about the appropriateness of classroom support strategies. This prompted me to consider how power inequalities affected participants' emotional and social well-being. I also developed a deeper understanding of participants' sense of frustration and anxiety when professionals' awareness and attitude towards DCD/dyspraxia prevented them from using accommodations that they knew would enhance their academic performance.

Impact on dissemination

Staley and Minogue (2006) suggest that service user involvement can lead to research being shared beyond the academic and research audiences typically targeted by professional researchers. Sharing a film about user involvement in this study on YouTube, and its promotion via the Dyspraxia Foundation, has extended the reach of the project and, we hope, has helped to raise awareness of DCD/dyspraxia amongst a wider audience. Staley and Minogue (2006) argue that service user researchers have a strong drive to share their findings, and Reference Group members were indeed passionate about co-presenting and co-authoring papers and posters to raise awareness of dyspraxia. Indeed, joint dissemination was limited more by my time restrictions than by a lack of enthusiasm from Reference Group members.

Personal impact on members of the Reference Group

Evidence of the impact of participation in the research on individual members of the Reference Group was provided by individuals throughout the project and is captured in a short film I commissioned for the INVOLVE Conference 2012. Individuals had different motivations for participating in the study. Some wanted to 'give something back' by sharing their experiences and strategies that had worked for them:

Bryn: I want to help with this kind of thing. I have quite a bit of experience of things that work.

Collin: I guess I'm here because I thought I could lend a hand.

Others were keen to see services and support improved for teenagers and young adults with DCD/dyspraxia because they had experienced a lack of support themselves:

Ellie: I find it's really hard for people of my age to get support.

Andrew: I would like more support for teenagers and eventually more support for adults.

Dawn: I wanted to make sure that there was support systems for teenagers and young adults that weren't in place when I was a teenager.

The sentiments expressed by Reference Group members reflect those of service users and carers in a study by Minogue et al (Minogue et al. 2005) who identified personal benefits arising from participation in the research process, including gaining knowledge about how health services and the research process worked, meeting people with a range of problems, talking to other service users, and developing research skills. Emotional benefits included gaining pleasure from being involved in something of interest, being part of a team and helping other people. Participants in Minogue's study also developed in terms of self-esteem and confidence. These benefits were reflected in comments made by members of the Reference Group in this study and are discussed below.

Bryn and Ellie both felt they'd benefitted from seeing the research process first-hand and hoped this would be useful in their future University studies. Bryn included his involvement in the Reference Group in his Personal Statement for University applications as a way of demonstrating understanding of his condition and his commitment to finding ways to work with it. Several members commented on the benefits of meeting others with DCD/dyspraxia and there were many times when they shared personal experiences and were surprised, but also reassured, that others had experienced the same. Imogen commented that she was very uncomfortable about disclosing her diagnosis to people who didn't have the condition as she thought they would tease her. As a result of her participation in the study however, she felt much more confident and able to explain dyspraxia and how it affected her. She also benefitted from the experience of co-presenting at a conference, commenting afterwards:

Imogen: I found the conference really useful, I would love to come again to raise awareness and give my views. The conference was really good experience and made me think what uni would be like if I went.

Ellie was also positive about the experience of co-presenting at a conference and felt that the skills and experience she gained would help her future studies:

Ellie: It was a great experience and as well as raising awareness of dyspraxia it will really help with my presenting skills on my course at uni which is always a good thing! The response we got from other people was also great, as everyone was really interested to hear our perspective as students, which is always refreshing!

While their role as collaborators in the research was limited by procedural issues and resource constraints, involvement of the Reference Group added value to the study by ensuring that the research prioritised issues that were important to young people with the condition. Furthermore, offering an insiders' perspective led to a deeper understanding of the issues that are of interest or concern to teenagers with DCD/dyspraxia than I would have been able to access as a non-dyspraxic researcher. There is also evidence to demonstrate the positive impact of participation in the research for Reference Group members. Personal benefits included growing in confidence, developing research skills and broadening personal understanding of dyspraxia. User involvement has helped to ensure that the research will have a positive impact on teenagers with DCD/dyspraxia, a group whose issues and concerns are under-researched and little recognised both in research and in clinical practice.

Chapter summary

In this chapter I evaluated and reflected on the use of interpretative phenomenological analysis as a methodological framework for this study, considering the study's strengths and limitations and my personal influence on the research process and findings. Particular consideration was given to the impact of user involvement on the study and on members of the Reference Group. What remains now is to consider what should be concluded about the issues that were investigated and how these findings might be used to benefit teenagers with DCD/dyspraxia and the adults who live or work with them. In the final chapter I review the study findings in relation to the research question and summarise the study's contribution to theory, practice and IPA for occupational therapists, other professionals and the voluntary agencies that support young people with DCD/dyspraxia.

Chapter 9

Conclusion

Chapter 9: Conclusion

This study offers an in-depth qualitative perspective on the lived experience of a group of teenagers with DCD/dyspraxia. By adopting an interpretative phenomenological approach, the study gives insight into the contemporaneous understandings and experiences of DCD/dyspraxia from the perspective of teenagers living with the condition. This understanding was enhanced by the involvement of a Reference Group of older teenagers/young adults with dyspraxia who brought an ‘insiders’ perspective’ to the interpretative process. In this final concluding chapter I review the research aims and objectives and summarise the new understandings about DCD/dyspraxia that the study brought forth. I also highlight the contribution that this study makes to self-efficacy theory and the practice of IPA. The involvement of service users is offered as a particular and novel methodological contribution. I identify the study’s contributions to theory and practice for occupational therapists, for other professionals, for parents and for voluntary agencies such as the Dyspraxia Foundation that support people affected by DCD/dyspraxia. Finally I make recommendations for future research based on the findings of this study.

A review of the research aim and objectives

The aim at the start of the study was to find out how teenagers with DCD/dyspraxia experience life from their own contemporaneous perspective. Within this aim I hoped to achieve the following objectives:

- To identify areas of interest and concern to teenagers with DCD/dyspraxia, and explore teenagers’ perspectives on the impact that DCD/dyspraxia has on their lives;
- To identify how parents, professionals and organisations such as the Dyspraxia Foundation might provide better support for teenagers with DCD/dyspraxia; and
- To identify directions for future research with teenagers with DCD/dyspraxia.

In the following sections I demonstrate how these objectives were met and in some cases exceeded, and the new understandings that the study brought forth.

New understandings about DCD/dyspraxia

The study advances knowledge of the lived experience of DCD/dyspraxia during adolescence. The majority of previous research has focused on children with DCD/dyspraxia aged 7-11 years as this is the age when motor performance deficits are typically identified because of their impact on social, emotional and academic performance (Clark and Whittall 2011). This study contributes to the very limited knowledge about teenagers with DCD/dyspraxia, a population whose issues and concerns are under-researched and little recognised in research and clinical practice. Key study findings are summarised in Table 12.

Table 12: Key research findings

Key research findings

- There are three domains of concern to teenagers with DCD/dyspraxia: activities of daily living; academic performance and social participation.
- The study broadens understanding of the impact of DCD/dyspraxia on activity and participation.
- Self-efficacy is a strong influence on the lived experience of DCD/dyspraxia affecting teenagers' confidence in their ability to perform academic, social and self-care tasks.
- For many teenagers, DCD/dyspraxia is more than just a physical construct.

Teenagers' perspectives on the functional domains of interest and concern to them

The conceptual framework presented in Chapter 7 is a novel means of illustrating teenagers' perspectives about the performance areas of concern to them and the impact of personal and environmental factors on their performance of everyday activities, thus achieving the first objective. The findings extend beyond the original study objectives however, as during the analytical process self-efficacy emerged as an important factor influencing not only teenagers' mastery and performance of activities, but also their sense of identity and agency, their emotional resilience and ambition for the future. The conceptual framework advances knowledge of DCD/dyspraxia by highlighting the impact of self-efficacy on teenagers' lived experience, and by illustrating the complex interaction of factors that influence and are influenced by DCD/dyspraxia during adolescence.

The impact of DCD/dyspraxia on activity and participation

The study furthers understanding of the impact of DCD/dyspraxia on activity and participation, areas in which previous research has been limited in both scope and volume (Magalhães, Cardoso and Missiuna 2011). Despite a proliferation of research about DCD/dyspraxia in recent years, remarkably few studies have explored the impact of DCD/dyspraxia on daily activity and participation, even though this is required for a diagnosis of DCD (American Psychiatric Association 2013) and is emphasized in EACD guidelines for the diagnosis, assessment and treatment of DCD (Blank et al. 2012). Furthermore, information has usually been gathered as an adjunct to measures of body function rather than as the main focus of the study and often reports parents' perspective rather than the perspective of young people themselves. Here, rigorous use of IPA enabled a rich, contemporaneous account of the lived experience of teenagers with DCD/dyspraxia to be explored. The study therefore extends the findings of previous research which, as demonstrated in Chapter 2,

has been dominated by positivist approaches with a bias towards younger children and a focus on clinical imperatives such as differential diagnoses, efficacy of assessment tools and intervention approaches.

Broadening understanding of the self-efficacy of young people with DCD/dyspraxia

The findings broaden understanding of the self-efficacy of teenagers with DCD/dyspraxia beyond the physical domain, the main focus of previous efficacy-related studies in the area of DCD/dyspraxia. The impact of teenagers' confidence in their ability to perform academic, social and self-care tasks has not previously been recognised and is not usually assessed in clinical practice (Poulsen et al. 2014). This is an important omission as, has been demonstrated, self-efficacy influences motivation and persistence to achieve tasks and activities. Moreover, the findings suggest that self-efficacy perceptions may help to explain the puzzling variations in the performance of young people with similar motor/cognitive capacity that is often observed by parents and clinicians. The study demonstrates the need to understand the efficacy-perceptions of teenagers with DCD/dyspraxia in order to develop appropriate interventions that reduce the risk of secondary consequences of low self-efficacy, including disengagement, lowering of standards and underachievement. All of these factors may have long term negative consequences for teenagers' health, emotional, economic and social well-being.

Demonstrating that for many teenagers, DCD/dyspraxia is more than a physical construct

This study advances knowledge of DCD/dyspraxia by demonstrating that it is more than just a physical construct (Alloway, Rajendran and Archibald 2009, Chen et al. 2013, Rigoli, Piek and Ooserlann 2012). While participants defined themselves as having a motor coordination disorder, the findings suggest that their deficits are more pervasive than current definitions of DCD imply. Participants identified a range of additional non-motor deficits that had a notable impact on their performance of daily activities at home, at school and during leisure activities. Furthermore, the findings support emerging research from the adult literature and anecdotal evidence from adults including members of the Reference Group, suggesting that non-motor difficulties may have more impact on performance of daily activities than poor motor coordination during adolescence. This is because teenagers have developed the motor skills necessary to perform everyday motor tasks, such as getting dressed, through persistent effort and practice during their younger years.

Contribution to self-efficacy theory

This study contributes to self-efficacy theory by offering a deeper understanding of the perceived efficacy of a group of adolescents whose performance of everyday activities is challenged by the physical and non-motor difficulties associated with DCD/dyspraxia.

Previous research into the self-efficacy of adolescents has focused on academic skills (Bandura 2012, Zimmerman, Bandura and Martinez-Pons 1992), social (Karademas 2006, Muris 2002) and self-regulatory skills (Major, Martinussen and Wiener 2013), sport and physical activity (Dishman et al. 2004), and career aspirations (Bandura et al. 2001). The findings of this study contribute to knowledge about self-efficacy in adolescence by suggesting ‘activities of daily living’ as an additional and important domain of concern. This reflects teenagers’ beliefs about their capacity to develop the skills necessary for them to live as independent adults in the future. Whilst efficacy for activities of daily living has been examined in adult and elderly populations (Hellström et al. 2003, Maujean and Davis 2013), it has not been the focus of research in adolescence. This is surprising given that adolescence is a time when young people expect and are expected to develop greater independence. Teenagers’ self-efficacy for activities of daily living and the impact of conditions such as DCD/dyspraxia on adolescents’ self-efficacy is therefore an area worthy of further investigation. This would require the development of a valid and reliable ‘self-efficacy for ADL’ assessment tool, which would be of particular relevance to occupational therapists both for the purposes of research and for use in clinical practice.

This study furthers understanding of the link between cognitive processing skills and self-efficacy by demonstrating the impact of poor executive functioning on mastery experiences. It is through positive mastery experiences that individuals develop confidence in their ability to perform an activity (Bandura 1977, 1994). Teenagers with DCD/dyspraxia however, struggled to master even seemingly simple activities, such as using cutlery and tying shoe laces, because their difficulties made it hard for them to identify the strategies that enabled their previous performance, to apply those strategies consistently, and to adapt their performance when they encountered problems. Consequently, participants lacked confidence in their ability to perform activities and were less motivated to persist when they encountered difficulties or received negative feedback from others. By demonstrating that people with poor cognitive processing skills have low self-efficacy for certain tasks, the study supports Bandura’s theory that mastery experiences exert a strong influence on efficacy perceptions. It also adds to Bandura’s theory by suggesting that people with poor cognitive processing skills may be at greater risk of low self-efficacy because they have difficulty mastering activities.

Participants were prepared to work hard to master specific tasks that were important to them, supporting Bandura’s theory that people with positive efficacy perceptions set themselves high goals and work hard to achieve them (Bandura 1994). The study extends Bandura’s ideas however, by demonstrating that participants felt it was impossible for them to achieve a high level of

competence across all domains. They therefore prioritized activities that were personally meaningful and relevant, and withdrew effort from activities in which they doubted their competence. The findings further demonstrate that a poor sense of efficacy in some activities (for example sporting skill) did not necessarily affect a person's overall sense of efficacy. Moreover, it was revealed that a person can hold differing views of their self-efficacy across different performance areas, for example across academic, social and self-regulatory domains. These findings support the argument for self-efficacy as a multi-dimensional, rather than a global concept (Bandura et al. 2001, Zimmerman 2000).

Contrary to Bandura's theory (1994), the findings of this study indicate that teenagers who enter adolescence with a poor sense of efficacy do not necessarily transfer their anxieties and vulnerabilities to new situations. This was most apparent in Billy's accounts. Despite appearing stressed and anxious at age 13, there was a reduction in anticipatory anxiety and an increase in coping efficacy through successful mastery experiences as he got older. His coping efficacy was enhanced by the support of professional counsellors and positive interactions with his parents and other influential adults over the course of the study. The findings suggest therefore, that the outlook for teenagers with DCD/dyspraxia who enter secondary school with a low sense of efficacy is not as gloomy as Bandura's theory predicts if teenagers receive appropriate support to enable positive mastery experiences.

Contribution to IPA theory and practice

Qualitative approaches allow for rich in-depth, exploration of human behaviour, and are particularly useful in the study of people's experience of health and illness (Lyons 2011). This study contributes to the growing body of research employing one particular qualitative methodology, IPA, to explore the lived experience of a health condition, DCD/dyspraxia. IPA is a relatively new research approach (Smith, Flowers and Larkin 2009)) which is increasingly used by occupational therapists to enable the deeper understanding of the lived experience of clients, carers and colleagues (Clarke 2009, Cronin-Davis, Butler and Mayers 2009, Hawtin and Sullivan 2001, Pettican and Prior 2011). This study adds to evidence demonstrating the application of IPA by occupational therapy researchers, and supports arguments for IPA as a useful research tool for understanding humans as occupational beings and for influencing the development of relevant and meaningful occupational therapy services (Clarke 2009).

The majority of previous IPA research has been conducted with adult participants (Smith 2011). This study makes an important contribution to IPA by demonstrating its application with adolescents. The study demonstrates that teenagers are willing to participate in research involving quite lengthy

interviews when they understand a study's aims and objectives and the research addresses an issue that is important and meaningful to them. Furthermore, prompted by an interview schedule that is relevant and clear, the study demonstrates that teenagers are able to reflect on their personal experience to provide rich, detailed accounts suitable for interpretative analysis.

Perhaps the most important and unique contribution that this study makes to IPA theory and practice, is to demonstrate that 'service users' can be involved in interpretative phenomenological research in a meaningful way whilst still adhering to the philosophical principles that underpin the approach. Despite practical and economic constraints, I have demonstrated that it is possible for service users to have meaningful involvement in the process of analysis as well as the study design, drawing on their shared experience of a phenomenon to help make sense of participants' experience. I argue that the involvement of the Reference Group enhanced, rather than threatened the hermeneutic process, by adding powerful insights from an insiders' perspective that I might not otherwise have accessed as a non-dyspraxic, adult researcher.

Contribution to occupational therapy theory

The study contributes to occupational therapy theory by providing support for the occupational domains of concern that underpin OT theory and practice, and by highlighting the impact of self-efficacy on mastery, an important therapeutic tool. Each of these contributions is examined in turn.

Central to the conceptual framework presented in Chapter 7 are three categories which represent the performance areas of concern to participants: activities of daily living, academic performance and social participation. These domains map closely to the three categories of occupational purpose included within the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend and Craik 2007): self-care, productivity and leisure. The close relationship between the functional domains of concern to participants and the occupational purposes incorporated into the CMOP-E support the validity of the CMOP-E as a theoretical model of occupational therapy. Whilst it is highly likely that my clinical background and understanding of occupational performance influenced the patterns and connections I saw in participants' accounts, the strength of participants' expressed beliefs about the impact of their difficulties on daily life activities support the importance of these three functional domains of concern. The plausibility of these occupational domains is further enhanced by members of the Reference Group who confirmed that they reflect their own priorities and experience.

The study contributes to occupational therapy theory by highlighting the impact of self-efficacy on skill mastery and occupational performance. Mastery is an important therapeutic tool and occupational therapists are skilled at grading and adapting activities and the environment to enable

a person to be successful at a task (Gage and Polatajko 1994). It has been noted however, that skills mastered in therapy sessions are not always translated beyond the clinical environment (Gage and Polatajko 1994). I argue that perceived efficacy may partly explain this variation in performance; if a person doubts their ability to perform a task they are less likely to choose to participate in that activity or to put time and effort into mastering it, even if they have the underlying capability to be successful, as demonstrated by participants' reluctance to master tying shoe laces when they had the option to wear slip-on shoes. The study therefore makes an important contribution to occupational therapy by drawing attention to the impact of perceived efficacy on mastery and occupational performance.

Implications for practice

In this section the implications of this study for occupational therapists, other professionals, and organisations supporting people with DCD/dyspraxia and their parents/carers, including the Dyspraxia Foundation are identified.

Implications for occupational therapists

As demonstrated in Chapter 7, the conceptual framework forms the basis of a clinical model of practice for occupational therapists working with teenagers with DCD/dyspraxia. Practice models provide a clear theoretical base and a structure to obtain information and develop interventions (Dunn 2011). The model of practice presented in Figure 10 now needs to be applied and tested to determine its applicability and suitability for research and clinical practice with teenagers with DCD/dyspraxia. The identification and/or development of suitable outcome measures is an area for future work; however, my colleagues and I have already integrated stages 1-3 of the practice model into our clinical practice and use the model to explain to teenagers, their parents and other professionals the role of the occupational therapist and how we aim to make a difference.

Implications for professionals working in health and education

The findings of this study have important implications for professionals (including occupational therapists) who determine whether or not a person is eligible for intervention by their performance on standardised motor assessments. This approach disadvantages young people who have the physical capacity to perform a task, but whose performance and participation is limited by a lack of confidence in their abilities. Professionals should therefore ensure that their service eligibility criteria do not disadvantage young people with 'borderline' motor difficulties who would benefit from intervention to enhance their self-efficacy and therefore their performance and participation in important activities at home, at school and in social settings. In the context of limited resources and increased demand on services, alternative methods of addressing the needs of this group of teenagers might include signposting to community groups that focus on fun and participation whilst

promoting the development of particular skills, and providing information about equipment and strategies to enable performance of activities of concern to teenagers. My occupational therapy team are developing a series of information sheets offering suggestions for tying shoe laces, brushing teeth and preparing food, as these were identified as common areas of concern to teenagers with DCD/dyspraxia.

The study demonstrates that DCD/dyspraxia is, for many teenagers, not just a physical construct, highlighting the need to raise awareness of the additional non-motor and self-regulatory difficulties experienced by many teenagers with the condition. Exploring teenagers' perceptions of their self-regulatory skills is important because academic abilities alone do not account for their academic achievement and career ambitions. It is vital therefore, for professionals and parents to understand teenagers' perceptions of their ability to manage their learning, as well as to assess and support their motor and cognitive abilities.

The findings highlight the importance of working with teenagers with DCD/dyspraxia to identify the support and strategies that enhance, rather than lower their academic and personal performance. Imposing equipment and solutions that do not match an individual's strengths and needs, even if they have proved successful for other teenagers, is disempowering and likely to lower a person's self-efficacy. Conversely, helping young people to understand their personal needs and identify accommodations that enable them to be successful will enhance their self-efficacy and agency, preparing them to take responsibility for decisions they will need to make as adults in the future.

The study indicates a need for a broad systems-based approach, as well as an individual approach, to address the environmental, institutional and attitudinal barriers to the performance and participation of teenagers with DCD/dyspraxia, particularly within the school context. Participants gave a clear message, confirmed by the Reference Group, that the support available in school for students with additional needs did not always meet the needs of teenagers with DCD/dyspraxia. In some cases, 'organisational solutions' actually increased teenagers' disadvantage by removing them from their usual environment and limiting opportunities to practice and rehearse strategies that might support their performance. There is therefore, a need for greater awareness and understanding of DCD/dyspraxia, not just amongst the teaching staff who have direct contact with students, but also amongst senior management teams and governing bodies who have responsibility to ensure the academic, social and emotional progress of all students in their care.

Implications for support organisations, including the Dyspraxia Foundation

A common theme throughout participants' accounts, confirmed by the Reference Group, was the need to raise awareness and understanding of DCD/dyspraxia and the impact of motor and non-

motor difficulties on teenagers' performance of daily activities at home, at school and in other settings. There is therefore a continuing need for organisations such as the Dyspraxia Foundation to raise awareness of this missed and misunderstood condition, especially amongst professionals who have a responsibility to support young people with DCD/dyspraxia and who are responsible for facilitating a diagnosis.

The findings suggest that teenagers lack confidence in their ability to articulate their difficulties, highlighting the need to provide tools to enable teenagers to explain their diagnosis to peers and the adults who have influence and the power to act on their behalf. The Dyspraxia Foundation is a central point of information and advice for people with DCD/dyspraxia living in the UK. The findings suggest a role for the Dyspraxia Foundation in gathering and sharing examples of ways that teenagers explain their diagnosis. The findings and experience of the Reference Group further indicate that publishing case studies in which teenagers and young adults with DCD/dyspraxia share their experience of living with the condition, will help to reduce teenagers' sense of isolation and promote sharing of strategies that support teenagers' performance at home, at school and in community settings. Participants' confusion and isolation arising from the diagnosis further suggests a role for the Dyspraxia Foundation to facilitate real or virtual networks to enable teenagers with DCD/dyspraxia to make contact others like themselves. The findings of this research will be shared with teenagers, parents and professionals at Dyspraxia Foundation events, via their social media networks and in newsletters over the coming year.

This study identified the factors that teenagers felt enhanced or lowered their self-efficacy and performance of everyday activities, highlighting how parents, professionals and support organisations might enhance the performance of teenagers with DCD/dyspraxia in activities that matter to them. This information could be used by the Dyspraxia Foundation, occupational therapists and other professionals to promote awareness of the leisure activities and contexts that offer a more suitable match for the abilities of teenagers with DCD/dyspraxia, thus promoting their physical health and their social and emotional well-being.

The enhanced sense of efficacy for collective agency among participants and Reference Group members was an unanticipated and indirect benefit of participation in the study and appeared to have a positive impact on their confidence and emotional well-being. The value and benefit of collective agency for young people with DCD/dyspraxia is particularly relevant to support organisations such as the Dyspraxia Foundation, who offer a voice to young people affected by the condition. Engaging young people with DCD/dyspraxia in activities to raise awareness of dyspraxia

and promote the strategies that support their performance will benefit both the individuals involved and the wider community of teenagers affected by the condition.

Directions for future research and practice development

As described in Chapter 2, teenagers with DCD/dyspraxia are under-represented in the research literature and find it harder than younger children to access services. The findings of this study suggest many areas for future research and practice development. Those I consider a priority are summarised below.

The findings indicate the need for further study to examine the impact of personal and environmental factors on social, academic and occupational outcomes for young people with DCD/dyspraxia during adolescence. Such factors include gender, the severity of a person's motor difficulties and the co-occurrence of difficulties with speech/language, attention and executive functions. The need to identify factors influencing the emotional and social resilience of teenagers with DCD/dyspraxia including the use of humour as a coping strategy was highlighted as a particular focus for further study. Understanding the impact of these factors will enable the identification of young people most at risk of poorer outcomes so that resources and support can be directed appropriately.

Self-efficacy emerged as a strong, recurrent theme as discussed in Chapter 7. Findings suggest the need to develop a tool that measures teenagers' self-efficacy for activities of daily living. Rigorous construction and testing of such a tool would ensure its utility for clinical practice and research and would enable the measurement of changes in teenagers' perceived efficacy for task performance, a useful and valid outcome measure within a client-centred approach.

There is a need to examine the factors that influence teenagers' efficacy perceptions and their influence on teenagers' motivation to pursue and master self-care, academic and social skills. This understanding will help occupational therapists and other professionals to develop interventions that enhance teenagers' performance and satisfaction with their performance of daily activities. The findings also suggest the value of examining the relationship between self-efficacy and depression/anxiety in young people with DCD/dyspraxia. The impact of anxiety-management interventions on perceived efficacy for and performance of practical tasks such as handling sharp tools and equipment is an area worthy of further study.

Participants' experience of secondary school and the risk of academic underachievement emerged as a strong theme and is an area that has received little previous attention in the research literature. The findings indicate the need for further exploration of the qualitative experience of school for

teenagers with DCD/dyspraxia so that relevant interventions and support to promote better academic outcomes can be developed. The need for further information and guidance for teachers to enable them to recognise, understand and support teenagers with DCD/dyspraxia was highlighted. I intend to work with the Dyspraxia Foundation to develop a guide for secondary school teachers that will enable them to promote the academic performance, well-being and social participation of students with DCD/dyspraxia.

The findings further indicate the need to explore self-efficacy for self-regulated learning among teenagers with DCD/dyspraxia and its relationship with academic achievement. This would enable the development of support and interventions to address the non-motor difficulties experienced by teenagers with DCD/dyspraxia as these are currently under-recognised and little support is provided for these at school.

Temporal changes evident in the narratives of participants described in Chapter 5 and discussed in Chapter 7 indicate the need for long term cohort studies to track changes in the lived experience of young people with DCD/dyspraxia from their own perspective as they progress through adolescence. Such understanding will enable the development of targeted interventions for teenagers at particular stages of their personal and academic development.

In Chapter 7 I proposed a conceptual framework illustrating the complex interaction of factors that influence the occupational performance of teenagers with DCD/dyspraxia in functional domains of concern to them. The framework also highlights the impact of self-efficacy on teenagers' sense of identity and agency, their emotional resilience and ambition for the future. I proposed that the conceptual framework forms the basis of a clinical model of practice for occupational therapists working with teenagers with DCD/dyspraxia. Such a model needs to be applied and tested in practice and research to determine its applicability, validity and clinical utility. This is an area that I hope to address through my post-doctoral work.

The study highlights the need for further research to examine the impact of occupational therapy on teenagers' activity and participation, on their sense of identity, efficacy for managing activities of adulthood, their sense of agency and emotional resilience. This would require the rigorous development and testing of outcome measures through research and practice to ensure their validity and clinical utility. Finally, as demand for statutory services and support from organisations such as the Dyspraxia Foundation increases, the study highlights the need to identify new ways of working to support teenagers with DCD/dyspraxia. Such methods include empowering young people through the provision of online information and support, and harnessing the benefits of collective

agency through the development of real and virtual communities for teenagers with DCD/dyspraxia, as highlighted by this study.

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Appendices

Appendix A: Literature search strategy

CINAHL (EBSCOhost) 'What do we know about teenagers with DCD/dyspraxia?'

- 01 'developmental coordination disorder*' OR 'developmental co-ordination disorder*' OR DCD OR dyspraxi* OR clums* OR 'motor skills disorder'
- 02 MM Motor Skills Disorders
- 03 1 OR 2
- 04 3 NOT verbal OR acquire*
- 05 teenage* OR adolesc* OR 'young adult*' OR 'young people' OR 'young person*' OR youth
- 06 4 AND 5

Limiters: age: adolescent 13-18 years

English language

Publication date 1989-2014

Peer reviewed articles

CINAHL (EBSCOhost) 'How easy is it for teenagers with DCD/dyspraxia to access occupational therapy?'

- 01 'developmental coordination disorder' OR 'developmental co-ordination disorder'
- 02 'service model*'
- 03 'pathway*'
- 04 'guideline*'
- 05 'protocol*'
- 06 'service*'
- 07 'occupational therapy*'
- 08 1 and 2
- 09 1 and 3
- 10 1 and 4
- 11 1 and 5
- 12 1 and 6
- 13 8 and 7
- 14 9 and 7
- 15 10 and 7
- 16 11 and 7
- 17 12 and 7
- 18 13 OR 14 OR 15 OR 16 OR 17

Limiters: English language

Publication date 2003 – 2014

Appendix B: Full text articles accessed for eligibility with reasons for exclusion - How does DCD/dyspraxia affect young people during adolescence?

	Articles accessed	Reason for exclusion
1	Anckarsäter, H., Lundström, S., Kollberg, L., Kerekes, N., Palm, C., Carlström, E., Långström, N., Magnusson, P. K. E., Halldner, L., Bölte, S., Gillberg, C., Gumpert, C., Råstam, M., and Lichtenstein, P. (2011) 'The Child and Adolescent Twin Study in Sweden (CATSS)'. <i>Twin Research and Human Genetics</i> 14 (6) 495-508	Content: Paper provides an overview of the methods and assessments used for a longitudinal study. Findings are not reported.
2	Astill, S. (2007) 'Can Children with Developmental Coordination Disorder Adapt to Task Constraints when Catching Two-Handed?' <i>Disability and Rehabilitation</i> 29 (1), 57-67	Age: Participants aged 7-10 years
3	Baerg, S., Cairney, J., Hay, J., Rempel, L., Mahlberg, N., and Faught, B. E. (2011) 'Evaluating Physical Activity using Accelerometry in Children at Risk of Developmental Coordination Disorder in the Presence of Attention Deficit Hyperactivity Disorder'. <i>Research in Developmental Disabilities</i> 32 (4) 1343-1350	Age: participant mean age 12 years.
4	Barnett, A. and Henderson, S. E. (1992) 'Some Observations in the Figure Drawings of Clumsy Children'. <i>The British Journal of Educational Psychology</i> 62 (Pt 3), 341-355	Age: participant mean age 8.8 years
5	Beutum, M., Reinie C., Bundy A. (2013) 'Comparing activity patterns, biological and family factors in children with and without developmental coordination disorder'. <i>Physical and Occupational Therapy in Pediatrics</i>	Age: participants aged 7-11 years
6	Bejerot, S. and Humble, M. B. (2013) 'Childhood Clumsiness and Peer Victimization: A Case-Control Study of Psychiatric Patients'. <i>BMC Psychiatry</i> 13, 68-68	Study focus & sample: Participants had a primary diagnosis of ADHD &/or autism – no diagnosis of DCD. Study examines relationship between poor motor skills associated and risk of peer victimization in people with ADHD/ASD
7	Bejerot, S., Plenty, S., Humble, A., and Humble, M. B. (2013) 'Poor Motor Skills: A Risk Marker for Bully Victimization'. <i>Aggressive Behavior</i> 39 (6), 453-461	Study focus & sample: Participants had a primary diagnosis of ADHD &/or autism – no diagnosis of DCD. Study examines relationship between poor motor skills associated and risk of peer victimization in people with ADHD/ASD
8	Cairney, J., Kwan, M. Y. W., Hay, J. A., and Faught, B. E. (2012) 'Developmental Coordination Disorder, Gender, and Body Weight: Examining the Impact	Age: Mean participant age 11.46 years.

	of Participation in Active Play'. <i>Research in Developmental Disabilities</i> 33 (5) 1566-1573	
9	Cairney, J., Hay, J., Faight, B., Mandigo, J., and Flouris, A. (2005) 'Developmental Coordination Disorder, Self-Efficacy Toward Physical Activity, and Play: Does Gender Matter?' <i>Adapted Physical Activity Quarterly</i> 22 (1) 67-82	Age: Participant mean age 11.46 years
10	Cairney, J., Hay, J., Veldhuizen, S., and Faight, B. (2011) 'Assessment of Body Composition using Whole Body Air-Displacement Plethysmography in Children with and without Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 32 (2), 830-835	Age: Participant mean age 12.4 years
11	Cairney, J., Hay, J. A., Wade, T. J., Faight, B. E., and Flouris, A. (2006) 'Developmental Coordination Disorder and Aerobic Fitness: Is it all in their Heads Or is Measurement Still the Problem?'. <i>American Journal of Human Biology: The Official Journal of the Human Biology Council</i> 18 (1), 66-70	Age: Participant mean age 11.4 years
12	Cairney, J., Hay, J., Faight, B., Mandigo, J., and Flouris, A. (2005) 'Developmental Coordination Disorder, Self-Efficacy Toward Physical Activity, and Play: Does Gender Matter?' <i>Adapted Physical Activity Quarterly</i> 22 (1), 67-82	Age: Participant mean age 11.4 years
13	Cairney, J., Hay, J. A., Faight, B. E., Flouris, A., and Klentrou, P. (2007) 'Developmental Coordination Disorder and Cardiorespiratory Fitness in Children'. <i>Pediatric Exercise Science</i> 19 (1), 20-28	Age: Participant mean age 11.4 years
14	Campbell, W. N., Missiuna, C., and Vaillancourt, T. (2012) 'Peer Victimization and Depression in Children with and without Motor Coordination Difficulties'. <i>Psychology in the Schools</i> 49 (4) 328-341	Age: Participant mean age 10 years 9 months
15	Chen, H. and Cohn, E. S. (2003) 'Social Participation for Children with Developmental Coordination Disorder: Conceptual, Evaluation and Intervention Considerations'. <i>Physical & Occupational Therapy in Pediatrics</i> 23 (4), 61-78	Content: Narrative review of previous research. Primary research papers included in review where appropriate
16	Chirico, D., O'Leary, D., Cairney, J., Klentrou, P., Haluka, K., Hay, J., and Faight, B. (2011) 'Left Ventricular Structure and Function in Children with and without Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 32 (1) 115-123	Age: Participants aged 12 years
17	Cousins, M. and Smyth, M. M. (2003) 'Developmental Coordination Impairments in Adulthood'. <i>Human Movement Science</i> 22 (4-5) 433-459	Age: Participants aged 18-65
18	Cummins, A., Piek, J. P., and Dyck, M. J. (2005) 'Motor Coordination, Empathy, and Social Behaviour in School-Aged Children'. <i>Developmental Medicine</i>	Age: Participant mean age 9.11 years

	<i>and Child Neurology</i> 47 (7), 437-442	
19	de Castelnaud, P., Albaret, J., Chaix, Y., and Zanone, P. (2007) 'Developmental Coordination Disorder Pertains to a Deficit in Perceptuo-Motor Synchronization Independent of Attentional Capacities'. <i>Human Movement Science</i> 26 (3) 477-490	Content: While the study includes YP with DCD aged 8-13 years, findings are mostly reported for the group as a whole. Few findings are reported for the group of YP with DCD aged 12-13 years specifically. Findings suggest possible neural explanations for the disorder, but add little to knowledge about how DCD affects YP during adolescence.
20	Dewey, D., Cantell, M., and Crawford, S. G. (2007) 'Motor and Gestural Performance in Children with Autism Spectrum Disorders, Developmental Coordination Disorder, and/or Attention Deficit Hyperactivity Disorder'. <i>Journal of the International Neuropsychological Society</i> 13 (2) 246-256	Age: Mean age of participants with DCD 11 years.
21	Dey, A., Barnsley, N., Mohan, R., McCormick, M., McAuley, J. H., and Moseley, G. L. (2012) 'Are Children Who Play a Sport Or a Musical Instrument Better at Motor Imagery than Children Who do Not?' <i>British Journal of Sports Medicine</i> 46 (13) 923-926	Age: Mean participant age 10 years.
22	Diamond, N., Downs, J., and Morris, S. (2014) "'the Problem with Running"--Comparing the Propulsion Strategy of Children with Developmental Coordination Disorder and Typically Developing Children'. <i>Gait & Posture</i> 39 (1), 547-552	Age: Participants aged 9-12 years
23	Dyck, M. and Piek, J. (2010) 'How to Distinguish Normal from Disordered Children with Poor Language Or Motor Skills'. <i>International Journal of Language & Communication Disorders</i> 45 (3) 336-344	Age: Mean participant age 8.55 years
24	Dyck, M. J., Piek, J. P., and Patrick, J. (2011) 'The Validity of Psychiatric Diagnoses: The Case of 'specific' Developmental Disorders'. <i>Research in Developmental Disabilities</i> 32 (6) 2704-2713	Age: Mean participant age 8.55 years
25	Dyck, M. J., Piek, J. P., Hay, D. A., and Hallmayer, J. F. (2007) 'The Relationship between Symptoms and Abilities in Autism'. <i>Journal of Developmental and Physical Disabilities</i> 19 (3) 251-261	Age: Mean participant age 8.55 years
26	Edmonds, C. (2012) "'Diff-ability" not "Disability": Right-brained thinkers in a left-brained education system.' <i>Support for Learning</i> . 27 (3) 129-135	Age, content & methodology: Participants aged 19-55. Qualitative findings are limited & focus on childhood experience of school, rather than adolescence.
27	Faught, B. E., Hay, J. A., Cairney, J., and Flouris, A. (2005) 'Increased Risk for Coronary Vascular Disease in Children with Developmental	Age: Participants mean age 11.5 years

	Coordination Disorder'. <i>The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine</i> 37 (5), 376-380	
28	Faught, B. E., Rivilis, I., Klentrou, P., Cairney, J., Hay, J., and Liu, J. (2013) 'Submaximal Oxygen Cost during Incremental Exercise in Children with Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 34 (12) 4439-4446	Age: Participants aged 12 years
29	Fong, S. S. M., Lee, V. Y. L., Chan, N. N. C., Chan, R. S. H., Chak, W., and Pang, M. Y. C. (2011) 'Motor Ability and Weight Status are Determinants of Out-of-School Activity Participation for Children with Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 32 (6) 2614-2623	Age: Participant mean age 8.7 years
30	Goez, H. and Zelnik, N. (2008) 'Handedness in Patients with Developmental Coordination Disorder'. <i>Journal of Child Neurology</i> 23 (2) 151-154	Age: Participant mean age 7 years
31	Hendrix, C. G., Prins, M. R., and Dekkers, H. (2014) 'Developmental Coordination Disorder and Overweight and Obesity in Children: A Systematic Review'. <i>Obesity Reviews: An Official Journal of the International Association for the Study of Obesity</i> 15 (5), 408-423	Content: Systematic review. Primary research papers included where appropriate.
32	Hill, E. L., Bishop, D. V. M., and Nimmo-Smith, I. (1998) 'Representational Gestures in Developmental Coordination Disorder and Specific Language Impairment: Error-Types and the Reliability of Ratings'. <i>Human Movement Science</i> 17 (4-5) 655-678	Age: Participant mean age 9 years
33	Hill, E. L. (1998) 'A Dyspraxic Deficit in Specific Language Impairment and Developmental Coordination Disorder? Evidence from Hand and Arm Movements'. <i>Developmental Medicine & Child Neurology</i> 40 (6) 388-395	Age: Participant mean age 9 years
34	Hill, E. L. and Brown, D. (2013) 'Mood Impairments in Adults Previously Diagnosed with Developmental Coordination Disorder'. <i>Journal of Mental Health (Abingdon, England)</i> 22 (4), 334-340	Age & content: Participant mean age 29 years. Impact of motor difficulties in adulthood explored
35	Ho, A. K. and Wilmut, K. (2010) 'Speech and Oro-Motor Function in Children with Developmental Coordination Disorder: A Pilot Study'. <i>Human Movement Science</i> 29 (4) 605-614	Age: Participant mean age 11.5 years
36	Jeffries, S., Everatt, J. (2004) 'Working memory: Its role in dyslexia and other specific learning difficulties'. <i>Dyslexia</i> . 10 (3) 196-214	Age: Participant mean age 10 years
37	Johnson, D., Wade, M. (2009) 'Children at risk for developmental coordination disorder: Judgment of changes in action capabilities'. <i>Developmental Medicine and Child Neurology</i> . 51 (5) 397-403	Age: Mean age 11 years 6 months
38	Jongmans, M. J., Smits-Engelsman, B., and	Age: Participant with DCD mean age

	Schoemaker, M. M. (2003) 'Consequences of Comorbidity of Developmental Coordination Disorders and Learning Disabilities for Severity and Pattern of Perceptual-Motor Dysfunction'. <i>Journal of Learning Disabilities</i> 36 (6), 528-537	7.7 years
39	Kane, K. and Barden, J. (2014) 'Frequency of Anticipatory Trunk Muscle Onsets in Children with and without Developmental Coordination Disorder'. <i>Physical & Occupational Therapy in Pediatrics</i> 34 (1), 75-89	Age: Participant mean age 11 years
40	Kane, K. and Barden, J. (2012) 'Contributions of Trunk Muscles to Anticipatory Postural Control in Children with and without Developmental Coordination Disorder'. <i>Human Movement Science</i> 31 (3) 707-720	Age: Mean age 11 years
41	Kaplan, B. J., Wilson, B. N., Dewey, D., and Crawford, S. G. (1998) 'DCD may Not be a Discrete Disorder'. <i>Human Movement Science</i> 17 (4-5) 471-490	Age: Mean age 12 years
42	Kaplan, B. J., Dewey, D. M., Crawford, S. G., and Wilson, B. N. (2001) 'The Term Comorbidity is of Questionable Value in Reference to Developmental Disorders: Data and Theory'. <i>Journal of Learning Disabilities</i> 34 (6), 555-565	Age: Participant mean age 12 years
43	Kirby, A., Davies, R., Bryan, A. (2005) 'Do teachers know more about specific learning difficulties than General Practitioners?' <i>British Journal of Special Education</i> 32 (3) 122-126	Content: Evaluation of professional knowledge about DCD and other conditions. No insights into impact of DCD on daily life.
44	Kirby, A., Edwards, L., and Sugden, D. (2011) 'Emerging Adulthood in Developmental Co-ordination Disorder: Parent and Young Adult Perspectives'. <i>Research in Developmental Disabilities</i> 32 (4) 1351-1360	Age & content: Participants aged 17-25 years (mean age 20.5 years) with a focus on issues relating to adulthood, rather than adolescence.
45	Kirby, A. (2011) 'Dyspraxia Series: Part One. At Sixes and Sevens'. <i>The Journal of Family Health Care</i> 21 (4) 29-31	Content & age: Not primary research. Paper describes the presentation of DCD in children and adults.
46	Kirby, A., Sugden, D., Beveridge, S., Edwards, L. (2008) 'Developmental coordination disorder (DCD) in adolescents and adults in further and higher education'. <i>Journal of Research in Special Educational Needs</i> 8 (3) 120 - 131	Age: Participants aged 16-25 years, mean age 19.9 years
47	Lalanne, C., Falissard, B., Golse, B., and Vaivre-Douret, L. (2012) 'Refining Developmental Coordination Disorder Subtyping with Multivariate Statistical Methods'. <i>BMC Medical Research Methodology</i> 12, 107-107	Age: Participant mean age 8.1 years
48	Mackenzie, S. J., Getchell, N., Deutsch, K., Wilms-Floet, A., Clark, J. E., and Whittall, J. (2008) 'Multi-Limb Coordination and Rhythmic Variability Under Varying Sensory Availability Conditions in	Age: Participants are children with DCD aged 7 years and adults.

	Children with DCD'. <i>Human Movement Science</i> 27 (2), 256-269	
49	Missiuna, C., Moll, S., Law, M., King, S., and King, G. (2006) 'Mysteries and Mazes: Parents' Experiences of Children with Developmental Coordination Disorder'. <i>Canadian Journal of Occupational Therapy / Revue Canadienne D'Ergothérapie</i> 73 (1) 7-17	Sample: Paper reports part of a qualitative study, focusing on the lived experience of <u>parents</u> of young people with DCD. Findings relating to the young people are reported in other papers which are included in the literature review.
50	Missiuna, C., Cairney, J., Pollock, N., Campbell, W., Russell, D. J., Macdonald, K., Schmidt, L., Heath, N., Veldhuizen, S., and Cousins, M. (2014) 'Psychological Distress in Children with Developmental Coordination Disorder and Attention-Deficit Hyperactivity Disorder'. <i>Research in Developmental Disabilities</i> 35 (5), 1198-1207	Age: Participant with DCD have a mean age of 11.6 years, while those with DCD & ADHD combined have a mean age of 12 years.
51	Miyahara, M. and Piek, J. (2006) 'Self-Esteem of Children and Adolescents with Physical Disabilities: Quantitative Evidence from Meta-Analysis'. <i>Journal of Developmental & Physical Disabilities</i> 18 (3), 219-234	Content: Review of 13 studies including 7 studies examining the effects of 'minor physical disabilities (e.g. clumsiness, DCD)' and major physical disabilities on self-esteem. Studies relating to minor disabilities include yp aged 5-17 years, most samples aged 5-12 years. Studies with yp aged 13+ are included separately in this review.
52	Mon-Williams, M., Tresilian, J. R., Bell, V. E., Coppard, V. L., Nixdorf, M., and Carson, R. G. (2005) 'The Preparation of Reach-to-Grasp Movements in Adults, Children, and Children with Movement Problems'. <i>The Quarterly Journal of Experimental Psychology A: Human Experimental Psychology</i> 58A (7) 1249-1263	Content: Paper offers a critical review of theories - not primary research.
53	Novak, C., Lingam, R., Coad, J., and Emond, A. (2012) 'Providing More Scaffolding': Parenting a Child with Developmental co-ordination Disorder, a Hidden Disability'. <i>Child: Care, Health and Development</i> 38 (6) 829-835	Age: Mean participant age 8 years 7 months
54	Pearsall-Jones, J., Piek, J. P., Rigoli, D., Martin, N. C., and Levy, F. (2011) 'Motor Disorder and Anxious and Depressive Symptomatology: A Monozygotic Co-Twin Control Approach'. <i>Research in Developmental Disabilities</i> 32 (4) 1245-1252	Age: Participant mean age 12 years
55	Pearsall-Jones, J., Piek, J. P., Steed, L., McDougall, M. R., and Levy, F. (2011) 'Monozygotic Twins Concordant and Discordant for DCD: Two Sides to the Story'. <i>Twin Research and Human Genetics</i> 14 (1) 79-87	Age: Mean participant age 12.6 years
56	Pettit, L., Charles, J., Wilson, A. D., Plumb, M. S., Brockman, A., Williams, J. H. G., and Mon-	Age: DCD group mean age 10 years.

	Williams, M. (2008) 'Constrained Action Selection in Children with Developmental Coordination Disorder'. <i>Human Movement Science</i> 27 (2) 286-295	
57	Piek, J. P., Dyck, M. J., Francis, M., and Conwell, A. (2007) 'Working Memory, Processing Speed, and Set-Shifting in Children with Developmental Coordination Disorder and Attention-Deficit-Hyperactivity Disorder'. <i>Developmental Medicine & Child Neurology</i> 49 (9) 678-683	Age: Participant mean age 8 years
58	Piek, J., Dyck, M., Nieman, A., Anderson, M., Hay, D., Smith, L., McCoy, M., Hallmayer, J. (2004) 'The relationship between motor coordination, executive functioning & attention in school-aged children'. <i>Archives of Clinical Neuropsychology</i> . 19 (8) 1063-1076	Age: Participant mean age 10 years.
59	Piek, J. P., Dyck, M. J., Nieman, A., Anderson, M., Hay, D., Smith, L. M., McCoy, M., and Hallmayer, J. (2004) 'The Relationship between Motor Coordination, Executive Functioning and Attention in School Aged Children'. <i>Archives of Clinical Neuropsychology: The Official Journal of the National Academy of Neuropsychologists</i> 19 (8), 1063-1076	Age: Participant mean age 10.5 years
60	Pieters, S., De Block, K., Scheiris, J., Eyssen, M., Desoete, A., Deboutte, D., Van Waelvelde, H., and Roeyers, H. (2012) 'How Common are Motor Problems in Children with a Developmental Disorder: Rule Or Exception?' <i>Child: Care, Health and Development</i> 38 (1) 139-145	Age & content: Co-morbidity study. Participant mean age 9 years.
61	Pieters, S., Desoete, A., Van Waelvelde, H., Vanderswalmen, R., and Roeyers, H. (2012) 'Mathematical Problems in Children with Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 33 (4), 1128-1135	Age: Participant mean age 9 years
62	Poulsen, A. A., Ziviani, J. M., and Cuskelly, M. (2007) 'Perceived Freedom in Leisure and Physical Co-Ordination Ability: Impact on Out-of-School Activity Participation and Life Satisfaction'. <i>Child: Care, Health and Development</i> 33 (4) 432-440	Age: Participant mean age 11 years 7 months
63	Poulsen, A. A., Ziviani, J. M., Johnson, H., and Cuskelly, M. (2008) 'Loneliness and Life Satisfaction of Boys with Developmental Coordination Disorder: The Impact of Leisure Participation and Perceived Freedom in Leisure'. <i>Human Movement Science</i> 27 (2) 325-343	Age: Participant mean age 11 years 7 months
64	Poulsen, A. A., Ziviani, J. M., Cuskelly, M., and Smith, R. (2007) 'Boys with Developmental Coordination Disorder: Loneliness and Team Sports Participation'. <i>American Journal of Occupational Therapy</i> 61 (4) 451-462	Age: Participant mean age 11 years 7 months

65	Prunty, M., Barnett, A., Wlimut, K., Plumb, M. (2013) 'Handwriting speed in children with DCD: Are they really slower?' <i>Research in Developmental Disabilities</i> 34 (9) 2927-2936	Age: Participant mean age 10 years.
66	Querne, L., Berquin, P., Vernier-Hauvette, M., Fall, S., Deltour, L., Meyer, M., and de Marco, G. (2008) 'Dysfunction of the Attentional Brain Network in Children with Developmental Coordination Disorder: A fMRI Study'. <i>Brain Research</i> 1244, 89-102	Age: Participant mean age 9.9 years
67	Rösblad, B. and von Hofsten, C. (1994) 'Repetitive Goal-Directed Arm Movements in Children with Developmental Coordination Disorders: Role of Visual Information'. <i>Adapted Physical Activity Quarterly</i> 11 (2) 190-202	Age: Participant mean age 11 years 7 months
68	Silman, A., Cairney, J., Hay, J., Klentrou, P., and Faught, B. E. (2011) 'Role of Physical Activity and Perceived Adequacy on Peak Aerobic Power in Children with Developmental Coordination Disorder'. <i>Human Movement Science</i> 30 (3) 672-681	Age: Mean age 12 years
69	Sinani, C., Sugden, D., Hill, E. (2011) 'Gesture production in school vs. clinical samples of children with developmental coordination disorder (DCD) and typically developing children'. <i>Research in Developmental Disabilities: A Multi-disciplinary Journal</i> . 32 (4) 1270-80	Age: Participants aged 9-11 years
70	Sylvestre, A., Nadeau, L., Charron, L., Larose, N., and Lepage, C. (2013) 'Social Participation by Children with Developmental Coordination Disorder Compared to their Peers'. <i>Disability and Rehabilitation: An International, Multidisciplinary Journal</i> 35 (21) 1814-1820	Age: Participants aged 7-8 years
71	Tal-Saban, M., Zarka, S., Grottos, I., Ornoy, A., Shula, P. (2012) 'The functional profile of young adults with suspected developmental coordination disorder (DCD). <i>Research in Developmental Disabilities: A Multidisciplinary Journal</i> . 33 (6) 2193-202	Age: Participants aged 19-25 years
72	Toussaint-Thorin, M., Marchal, F., Benkhaled, O., Pradat-Diehl, P., Boyer, F., and Chevignard, M. (2013) 'Executive Functions of Children with Developmental Dyspraxia: Assessment Combining Neuropsychological and Ecological Tests'. <i>Annals of Physical and Rehabilitation Medicine</i> 56 (4) 268-287	Age: Participant mean age 10.3 years
73	van Swieten, L. M., van Bergen, E., Williams, J. H. G., Wilson, A. D., Plumb, M. S., Kent, S. W., and Mon-Williams, M. (2010) 'A Test of Motor (Not Executive) Planning in Developmental Coordination Disorder and Autism'. <i>Journal of</i>	Age: Mean age of older group with DCD 12 years.

	<i>Experimental Psychology: Human Perception and Performance</i> 36 (2) 493-499	
74	Whitall, J., Getchell, N., McMenamin, S., Horn, C., Wilms-Floet, A., and Clark, J. E. (2006) 'Perception-Action Coupling in Children with and without DCD: Frequency Locking between Task-Relevant Auditory Signals and Motor Responses in a Dual-Motor Task'. <i>Child: Care, Health and Development</i> 32 (6), 679-692	Age: Participant mean age 7 years
75	Williams, J., Anderson, V., Reddihough, D. S., Reid, S. M., Vijayakumar, N., and Wilson, P. H. (2011) 'A Comparison of Motor Imagery Performance in Children with Spastic Hemiplegia and Developmental Coordination Disorder'. <i>Journal of Clinical and Experimental Neuropsychology</i> 33 (3) 273-282	Age: Participants aged 8-12 years
76	Wilmot, K., Byrne, M., and Barnett, A. L. (2013) 'Reaching to Throw Compared to Reaching to Place: A Comparison Across Individuals with and without Developmental Coordination Disorder'. <i>Research in Developmental Disabilities</i> 34 (1), 174-182	Age: Participant mean age 8 years
77	Wilson, P., Kaplan, B., Crawford, S., Campbell, A., Dewey, D. (1998) 'Information processing deficits associated with developmental coordination disorder: a meta-analysis of research findings.' <i>Journal of Child Psychology and Psychiatry</i> 39 (6) 829-840	Age: Participant mean age 9 years
78	Wuang, Y., Wang, C., and Mao-Hsiung, H. (2012) 'Health-Related Quality of Life in Children with Developmental Coordination Disorder and their Parents'. <i>OTJR: Occupation, Participation and Health</i> 32 (4) 142-150	Age: Participant mean age 11.2 years
79	Yee-Pay Wuang, Chih-Chung Wang, and Mao-Hsiung Huang (2012) 'Health-Related Quality of Life in Children with Developmental Coordination Disorder and their Parents'. <i>OTJR: Occupation, Participation & Health</i> 32 (4), 142-159	Age: Participant mean age 11 years
80	Zwicker, J., Harris, S., Klassen, A. (2013) 'Quality of life domains affected in children with DCD: A systematic review.' <i>Child: Care, Health & Development</i> 39 (4) 562-580	Content: Review of 41 studies including participants aged 4-20 years. Analysis by whole group, not specifically by age. Relevant studies reviewed separately for eligibility & included where appropriate.

Appendix B: Full text articles accessed for eligibility with reasons for exclusion - How easy is it for teenagers with DCD/dyspraxia to access occupational therapy services?

	Articles accessed	Reason for exclusion
1	Dunford, C., Street, E., O'Connell, J., Kelly, J., and Sibert, J. R. (2004) 'Are Referrals to Occupational Therapy for Developmental Coordination Disorder Appropriate?'. <i>Archives of Disease in Childhood</i> 89 (2), 143-147	Age: participants aged 5-10 years. Content: paper examines whether children referred for OT with a presumptive diagnosis of DCD fulfilled the diagnostic criteria on assessment. Findings indicate that school nurses are better than teachers at recognising DCD. Study does not report parents' experience of accessing services.
2	Gaines, R., Missiuna, C., Egan, M., and McLean, J. (2008) 'Interprofessional Care in the Management of a Chronic Childhood Condition: Developmental Coordination Disorder'. <i>Journal of Interprofessional Care</i> 22 (5), 552-555	Content: Paper describes development of a collaborative approach to the care of children with DCD in Canada. Different funding & models of service provision means findings cannot easily be transferred to UK.
3	Green, D., Bishop, T., Wilson, B. N., Crawford, S., Hooper, R., Kaplan, B., and Baird, G. (2005) 'Is Questionnaire-Based Screening Part of the Solution to Waiting Lists for Children with Developmental Coordination Disorder?'. <i>British Journal of Occupational Therapy</i> 68 (1), 2	Content: Study examines reliability of parent & teacher completed questionnaires compared to clinical assessment for identifying DCD in children. Study does not examine how easy it is to access services from the perspective of young people/parents
4	McWilliams, S. (2005) 'Developmental Coordination Disorder and Self-Esteem: Do Occupational Therapy Groups have a Positive Effect?'. <i>British Journal of Occupational Therapy</i> 68 (9), 393	Content: Study examines intervention. Age: Participants are YP aged 6-11 years
5	Missiuna, C., Pollock, N., Egan, M., DeLaat, D., Gaines, R., and Soucie, H. (2008) 'Enabling Occupation through Facilitating the Diagnosis of Developmental Coordination Disorder'. <i>Canadian Journal of Occupational Therapy</i> 75 (1), 26	Content: Paper describes the role of the OT in recognising and facilitating the diagnosis of DCD. Focus is on the professional role, rather than the experience of YP/parents.
6	Missiuna, C. A., Pollock, N. A., Levac, D. E., Campbell, W. N., Sahagian Whalen, S. D., Bennett, S. M., Hecimovich, C. A., Gaines, B. R., Cairney, J., and Russell, D. J. (2012) 'Partnering for Change: An Innovative School-Based Occupational Therapy Service Delivery Model for Children with Developmental Coordination Disorder'. <i>Canadian Journal of Occupational Therapy</i> 79 (1), 41	Content: Paper describes a new school-based health service delivery model for YP with DCD in Canada. Differences between UK and Canada in funding/service delivery models means findings are not directly transferred to UK.
7	Miyahara, M., Butson, R., Cutfield, R., and Clarkson, J. E. (2009) 'A Pilot Study of Family-Focused Tele-Intervention for Children with Developmental Coordination Disorder: Development and Lessons	Content: Paper describes an innovative intervention approach for pre-teens with DCD in New Zealand.

	Learned'. <i>Telemedicine and e-Health</i> 15 (7), 707-712	
8	Peters, J. M., Henderson, S. E., and Dookun, D. (2004) 'Provision for Children with Developmental Co-Ordination Disorder (DCD): Audit of the Service Provider'. <i>Child: Care, Health and Development</i> 30 (5), 463-479	Age: Participants' mean age was 9 (respondents) to 11 (non-respondents) years. Findings therefore reflect experience of parents of younger children with DCD.
9	Peters, J. M. and Henderson, S. E. (2008) 'Understanding Developmental Coordination Disorder and its Impact on Families: The Contribution of Single Case Studies'. <i>International Journal of Disability, Development and Education</i> 55 (2), 97-111	Age: Participants aged 5-11 years.
10	Polatajko, H. J. and Cantin, N. (2005) 'Developmental Coordination Disorder (Dyspraxia): An Overview of the State of the Art'. <i>Seminars in Pediatric Neurology</i> 12 (4), 250-258	Content: Paper reviews intervention approaches & evidence of their efficacy.
11	Sugden, D. (2007) 'Current Approaches to Intervention in Children with Developmental Coordination Disorder'. <i>Developmental Medicine & Child Neurology</i> 49 (6), 467-471	Content: Paper is a review of intervention approaches.
12	Taylor, S., Fayed, N., and Mandich, A. (2007) 'CO-OP Intervention for Young Children with Developmental Coordination Disorder'. <i>Otjrr Occup Particip Health</i> 27 (4), 124	Content: Paper examines efficacy of an intervention approach for younger children with DCD.

Appendix C: Critical Appraisal of included papers

Qualitative studies

Paper details	Barnett A, Dawes H, Wilmut K (2013) <i>'Constraints and facilitators to participation in physical activity in teenagers with DCD: an exploratory interview study'</i> <u>Child: Care, health & development</u> 39 (3) 393-403	Fitzpatrick D, Watkinson EJ (2003) <i>'The lived experience of physical awkwardness: adults' retrospective views'</i> <u>Adapted Physical Activity Quarterly</u> 20 279-297
Clear evidence of study aims? Goal clear? Why important? Relevant?	Goal: To understand which factors constrain & facilitate participation in physical activities in teenagers with DCD Relevance: teenagers with DCD avoid physical activity, putting them at risk of poor physical fitness and long term health issues.	Goal: To seek an understanding of adults' past-lived experiences of physical awkwardness to better capture the feelings & meanings individuals ascribe to the phenomenon Relevance: testing the assumption that motor incoordination is accompanied by predictable negative affective experiences
Is qualitative method appropriate? Aim to interpret/illuminate actions or experiences? Does methodology address research goal?	Yes – to explore perceived constraints & facilitators to physical activity.	Yes – to gain insight into the affective experience & meanings individuals associated with them.
Is research design appropriate?	Yes – qualitative study to explore a specific issue through interview & content analysis	Justification for use of hermeneutic phenomenology provided.
Was the recruitment strategy appropriate? How were participants selected? Why were they appropriate to access knowledge sought? Discussion about recruitment issues	8 teenagers & their parents, recruited from larger research study into fitness of teenagers with DCD. Boys aged 13-15 years diagnosed with DCD: diagnosis confirmed by researchers Unclear how or why these particular individuals were selected for further study. Were they representative of the larger sample?	Volunteer participants willing to share their experience who felt they had experience of physical awkwardness Exclusion = no experience of physical awkwardness &/or illness/obesity/disability impacting on physical activity No standardised/independent verification of motor difficulties Gender bias – 10 women, 2 men
Was data collected in a way that addressed the research issues? Appropriate setting? Data collection method clear? Methods justified? Methods modified? Why & how? Is form of data clear? Is data saturation discussed?	Semi-structured interviews separately with YP and parents at home or in university setting Interview questions provided No discussion re data saturation	Face to face or telephone interviews (captured perspective of those with reduced mobility) Pilot interviews clarified interview process Participants asked to write about a previous experience, then to talk about it: justification for this approach provided Data saturation reached
Has the relationship between researcher & participants been	No evidence that this was considered.	No description or acknowledgement of impact of researchers on research process/analysis provided

considered? <i>Researcher role How researcher responded to events as they occurred.</i>		
Ethical issues addressed?	University ethical approval given	Individuals volunteered to participate having read study information. No evidence of external ethical review.
Data analysis sufficiently rigorous? <i>Process described? How were themes derived? How was data chosen to demonstrate analysis? Enough data to support findings? Considers contradictory findings? Bias considered?</i>	Coding system agreed by all authors Categorical content analysis used Implication that themes were chosen for their frequency of occurrence or divergence of views, rather than their richness/potential to illuminate understanding Number of participants who mentioned each theme presented throughout findings – frequency data not usually consistent with qualitative approaches which emphasise depth/richness of data rather than prevalence of themes Impression that findings were presented in a quantitative way that is less consistent with a qualitative study	‘Detailed reading’ approach and systematic development of themes by primary author described although detail is limited 3 other experts reviewed the process, although their qualifications as ‘experts’ & the level of their involvement is not clear
Clear statement of findings? <i>Evidence for & against? Credibility discussed? Findings discussed in relation to research question?</i>	Findings organised into 2 broad themes. Many short quotes provided as illustration – lacking richness/depth Emergent findings discussed with 3 experts/critical friends to ensure findings were plausible Findings related to research question ie. constraints/facilitators of physical activity were identified	Member checking of transcripts by participants. 4 themes identified that relate to research question Quotes used to support findings
How valuable is the research? <i>Contribution to knowledge apparent? Areas for further research identified? Transferable findings?</i>	Contributes to understanding re why some teenagers avoid physical activity, despite having the physical capacity to engage Need for greater awareness among teachers/community sports instructors to facilitate participation of teenagers with DCD highlighted Sample reflects heterogeneity of teenagers with DCD Lack of info about socio-economic status limits ability to apply to other populations (access to physical activity may be limited by family resources)	New knowledge re long term impact of experience of physical awkwardness in childhood Relevance of gender bias in relation to practice & further research discussed Need for further study to explore lived experience of physical awkwardness in children/young people identified Reader invited to draw his/her own conclusions about relevance of findings to own situation.

Paper details	Lingam R, Novak C, Emond A, Coad J (2014) ' <i>The importance of identity and empowerment to teenagers with DCD</i> ' <i>Child: Care, Health & Development</i> 40 (3) 309-318	Maciver, D., Owen, C., Flannery, K., Forsyth, K., Howden, S., Shepherd, C., Rush, R. (2011) ' <i>Services for children with developmental co-ordination disorder: the experiences of parents</i> ' <i>Child: Care, Health & Development</i> 37 (3) 422-429
Clear evidence of study aims? <i>Goal clear?</i> <i>Why important?</i> <i>Relevant?</i>	Goal: To gain an in-depth understanding of the experiences & aspirations of a group of young people living in the UK with DCD Relevance: previous research into parental perspective indicates a 'trajectory of troubles'; need to determine whether this perspective is shared by those living with the condition.	Goal: to explore parents' perceptions of their journey of accessing and engaging with services for their children with DCD Relevance: previous studies have focused on parents' views/feelings/experiences, but have not explored parents' experiences of receiving health & educational services post-diagnosis.
Is qualitative method appropriate? <i>Aim to interpret/illuminate actions or experiences?</i> <i>Does methodology address research goal?</i>	Yes – to gain an in-depth understanding of the lived experience	Yes – to explore parents' perceptions of the experience of accessing health service provision.
Is research design appropriate?	Justification for phenomenological hermeneutic approach using individual & group interview with visual prompts provided.	Yes - Focus groups with parents as key informants Thematic analysis.
Was the recruitment strategy appropriate? <i>How were participants selected?</i> <i>Why were they appropriate to access knowledge sought?</i> <i>Discussion about recruitment issues</i>	Clinical sample which may represent those with more severe coordination difficulties (necessary to reach thresholds for referral to clinical services) YP diagnosed with DCD, referred to OT services & were willing to share experience Presence of DCD confirmed by MABC score below 5 th percentile with evidence of impact of movement difficulties on daily life Presence of overlapping conditions = exclusion criteria 11 participants sampled for represent variation in age, area of residence, gender 7 boys, 4 girls aged 11-16 Ethnic profile matched local population	Parents of children diagnosed with DCD or who fulfil DSM-iv criteria for diagnosis, currently or recently (within 12 months) receiving services from an allied health professional. Families recruited by OTs who provided information about the project to eligible families
Was data collected in a way that addressed the research issues? <i>Appropriate setting?</i> <i>Data collection method clear?</i> <i>Methods justified?</i> <i>Methods modified? Why & how?</i>	Yes – individual interviews (n=11) & group discussion (n=7: no explanation for fewer in group discussion) Interviews enhanced by arts-based materials Questions identified with help of 2 other adolescents with DCD – relevant & meaningful	Focus groups facilitated by researchers No information about location of focus groups offered Examples of questions provided No reference to data saturation

<i>Is form of data clear? Is data saturation discussed?</i>	Interviews at home, groups in research centre No discussion re data saturation	
<i>Has the relationship between researcher & participants been considered?</i> <i>Researcher role How researcher responded to events as they occurred.</i>	Limited evidence of role of researcher on research process/interpretation Field notes written, but unclear how these were used to inform analysis	No discussion of researcher role and relationships with participants
<i>Ethical issues addressed?</i>	LREC approval. Informed consent procedures described	Ethical approval process described. No other ethical issues discussed.
<i>Data analysis sufficiently rigorous?</i> <i>Process described? How were themes derived? How was data chosen to demonstrate analysis? Enough data to support findings? Considers contradictory findings? Bias considered?</i>	Iterative process of analysis described Coding scheme developed Themes agreed by research team Quotes used to illustrate findings Researcher bias on theme prioritization not mentioned	Coding process described 2 researchers with support of a 3 rd Maximum of 2 quotes to illustrate each theme Some contradictory findings presented Recruitment bias not discussed, although families were drawn from 7 different services
<i>Clear statement of findings?</i> <i>Evidence for & against? Credibility discussed? Findings discussed in relation to research question?</i>	Findings clearly stated Findings related to research question Trustworthiness & credibility of findings discussed	4 themes presented
<i>How valuable is the research?</i> <i>Contribution to knowledge apparent? Areas for further research identified? Transferable findings?</i>	Contribution to knowledge (key messages) highlighted Directions for future work (practical) included Limitations re transferability acknowledged	Supports findings of previous studies indicating the challenge of accessing & engaging with therapy services (e.g. Rodger & Mandich 2005; Missiuna et al 2006). Adds to knowledge about continuing struggle post-diagnosis Identifies need for further study to support therapy services that focus on activity/participation rather than body functions Scottish study –access to NHS health provision similar to that in Wales/England.

Paper details	Missiuna C, Moll S, King S, Law M, King G (2006) ' <i>Missed and misunderstood: Children with coordination difficulties in the school system</i> ' <i>International Journal of Special Education</i> 21 (1) 53-67	Missiuna, C., Moll, S., Law, M., King, S., King, G. (2006) ' <i>Mysteries and mazes: Parents' experiences of children with DCD</i> ' <i>Canadian Journal of Occupational Therapy</i> 73 (1) 7-17
Clear evidence of study aims? Goal clear? Why important? Relevant?	Goal: To explore parents' perceptions of the early experiences & participation patterns of children with DCD, in particular their experience of education in the classroom & on the playground Relevance: DCD is a high prevalence disorder & there is growing evidence of the impact of poor motor coordination on everyday activities & academic achievement. Study adds to this understanding.	Goal: to explore the early experiences and participation patterns of children with DCD as perceived and reported by their parents Relevance: understanding the perspective of parents of YP with DCD, especially their interactions with health and school services helps to facilitate family-centred care. Understanding the environmental context & the meanings parents ascribe to their child's difficulties impacts on service delivery.
Is qualitative method appropriate? Aim to interpret/illuminate actions or experiences? Does methodology address research goal?	Yes – exploring parents' perceptions of the meanings of experiences of school system & the impact of the environmental context on children & families.	Yes – to explore parents' perceptions of the experiences & participation patterns of their children, and the meanings they ascribe to their child's difficulties.
Is research design appropriate?	Phenomenological approach Parents as key informants as they have a unique perspective on children's lives	Yes – Qualitative study, interviews Phenomenological analysis
Was the recruitment strategy appropriate? How were participants selected? Why were they appropriate to access knowledge sought? Discussion about recruitment issues	Purposeful sampling 13 families recruited from 3 clinical settings – parents opted in to study by contacting researchers No discussion re features of families who chose not to participate 10 boys, 3 girls aged 6-14 (mostly under 11) DCD confirmed by Movement ABC score below 15 th percentile (or previous reports indicating significant motor difficulties for 2 participants over age range for MABC) More diversity among children; parents were highly educated	Parents of 13 yp living in one area of Canada (2 regions of service delivery) Recruitment via professionals in schools, therapy agencies Purposive sampling to address the research question – participations were volunteers (implications noted) YP fulfilled criteria for DCD diagnosis Aged 6-14; 10 boys & 3 girls
Was data collected in a way that addressed the research issues? Appropriate setting? Data collection method clear? Methods justified? Methods modified? Why & how? Is form of data clear? Is data saturation	Semi-structured interviews & questionnaire data Followed up by focus groups or telephone interview Data saturation not mentioned in this paper	In-depth interviews with open-ended questions, supported by Strengths & Difficulties Q, and CAPE. Follow-up interview later. Data saturation achieved.

<i>discussed?</i>		
Has the relationship between researcher & participants been considered? <i>Researcher role</i> <i>How researcher responded to events as they occurred.</i>	On-going reflective analysis to identify & bracket assumptions Varied researcher perspectives identified as a strength that enabled a broader (rather than individual) analysis Triangulation & member-checking discussed	Interviewer was an OT – experienced researcher, but not knowledgeable about DCD On-going reflective analysis by interviewer reported.
Ethical issues addressed?	University ethical approval. No other ethical issues discussed.	No
Data analysis sufficiently rigorous? <i>Process described?</i> <i>How were themes derived?</i> <i>How was data chosen to demonstrate analysis?</i> <i>Enough data to support findings?</i> <i>Considers contradictory findings?</i> <i>Bias considered?</i>	Coding system developed by all 5 researchers Coding consistency checked Member-checking of themes via focus group or telephone interview Limitations acknowledged: only parents' perspective was gathered & all families had 2 well-educated parents.	Coding process developed by all members of research team Coding consistency between researchers established Member checking of transcripts via focus group or telephone interview Ongoing reflexive analysis by researchers Variations & contradictory findings reported
Clear statement of findings? <i>Evidence for & against?</i> <i>Credibility discussed?</i> <i>Findings discussed in relation to research question?</i>	4 broad themes: in the classroom, outside the classroom, the overall educational system & how teachers make a difference. Themes supported by quotes (not linked to individual names so difficult to know whether some parents were more represented than others)	2 broad themes with subthemes Credibility discussed Good use of quotes used to illustrate findings
How valuable is the research? <i>Contribution to knowledge apparent?</i> <i>Areas for further research identified?</i> <i>Transferable findings?</i>	Contribution – understanding perspective of parents regarding their children's experience of school – impact of difficulties secondary to motor difficulties highlighted. Need for increased awareness of primary & secondary symptoms of DCD among teachers highlighted. Findings may not transfer to families who are more deprived/less well educated	Supports findings of other studies indicating the challenge of accessing services for children with DCD (Maciver 2011; Stephenson & Chesson 2008). Implications for OT practice discussed – need for family-centred assessment, education of other professionals, promoting participation & mastery. Canadian study – service delivery models & cultural differences impact on transferability to UK

Paper details	Missiuna C, Moll S, King G, Law M (2007) 'A trajectory of troubles: Parents' impressions of the impact of developmental coordination disorder' <i>Physical and Occupational Therapy in Pediatrics</i> 27 (1) 81-101	Missiuna C, Moll S, King S, Stewart D, Macdonald K (2008) 'Life experiences of young adults who have coordination difficulties. <i>Canadian Journal of Occupational Therapy</i> 75 (3) 157-166
Clear evidence of study aims? Goal clear? Why important? Relevant?	Goal: To explore parents' perceptions of the experiences of children with DCD, focusing on their impressions of the emergence of developmental concerns in children with DCD over time Relevance: DCD has a high prevalence but little is known about the issues that persist in children and how they change over time.	Goal: To explore the effect of coordination difficulties on the life domains of adolescence & to identify the specific factors that support or hindered development & participation in education, employment, leisure & social participation Relevance: Little research into adolescence; little known about personal & environmental factors affecting adaptation. Relevance to clinical practice identified.
Is qualitative method appropriate? Aim to interpret/illuminate actions or experiences? Does methodology address research goal?	Yes – exploring parents' perspectives regarding the meaning of their children's experiences.	Yes – to explore the nature & meaning of everyday experience of young people with poor motor coordination
Is research design appropriate?	Phenomenological approach Parents key informants as they have a unique perspective on children's lives	Phenomenological approach using 2 in-depth interviews with each participant..
Was the recruitment strategy appropriate? How were participants selected? Why were they appropriate to access knowledge sought? Discussion about recruitment issues	Purposeful sampling 13 families recruited from 3 clinical settings – parents opted in to study by contacting researchers No discussion re features of families who chose not to participate 10 boys, 3 girls aged 6-14 (mostly under 11) i.e. appropriate gender ratio DCD confirmed by Movement ABC score below 15 th percentile (or previous reports indicating significant motor difficulties for 2 participants over age range for MABC)	Volunteer participants from university who reported motor difficulties affecting daily life in adolescence – may not represent all adults with DCD (high academic achievers) Diagnosis not pre-requisite for inclusion. Participants screened with questions from DCD-Q and about medical/learning history Participants able to articulate experience of motor coordination difficulties Gender bias – 4 male, 5 female.
Was data collected in a way that addressed the research issues? Appropriate setting? Data collection method clear? Methods justified? Methods modified? Why & how? Is form of data clear? Is data saturation	2 interviews, 2 nd to explore issues from 1 st in more depth Semi-structured interviews Additional questionnaires inc demographics, strengths & difficulties Example questions & use of probes to explore experiences provided Theoretical saturation reached.	2 interviews each carried out at university where recruitment took place. 2 nd interview to explore issues arising in first in more depth No modifications of data collection method reported. Data saturation achieved

<i>discussed?</i>		
Has the relationship between researcher & participants been considered? <i>Researcher role</i> <i>How researcher responded to events as they occurred.</i>	Limited evidence. Impact of researchers on recruitment, analysis & interpretation not addressed.	Researchers' professional backgrounds revealed, but impact of professional/personal roles on analysis & interpretation not discussed.
Ethical issues addressed?	University ethical approval. No other ethical issues discussed.	Ethical approval via university. No other ethical issues discussed.
Data analysis sufficiently rigorous? <i>Process described?</i> <i>How were themes derived?</i> <i>How was data chosen to demonstrate analysis?</i> <i>Enough data to support findings?</i> <i>Considers contradictory findings?</i> <i>Bias considered?</i>	Coding scheme described. Modifications to scheme made as new themes emerged. Themes supported by quotes (fewer for some themes than others) Contradictory findings included Member checking – transcript sent, focus group or telephone call to validate findings.	All researchers contributed to analysis. Iterative system of conceptual coding developed Analysis involved identification of interconnections between key categories & themes Variations in experience included Quotes used to illustrate findings – not attributed to participants making it difficult to track an individual's story Gender bias of sample not discussed
Clear statement of findings? <i>Evidence for & against?</i> <i>Credibility discussed?</i> <i>Findings discussed in relation to research question?</i>	Theme of a 'trajectory of troubles' organised into 7 sections. Difference in experiences with age discussed Limitations re sample size, selection & study design acknowledged	3 themes identified & discussed in relation to research question Variability in experience mentioned. Study limitations identified – sample size, homogeneity of sample (well-educated & resilient), diagnosis not confirmed, retrospective reflections on adolescence
How valuable is the research? <i>Contribution to knowledge apparent?</i> <i>Areas for further research identified?</i> <i>Transferable findings?</i>	Contribution to knowledge – increased understanding of changing impact of difficulties over time – social & emotional impact varies over time. Clinical implications identified Need for longitudinal studies & studies to identify factors that promote resilience identified.	Contribution to knowledge – coping trajectory is not necessary downward; many adults develop coping strategies. Clinical implications identified – need to consider ecological or environmental adaptations to facilitate participation. Findings may not be transferrable to adults who are less well educated/males

Paper details	Novak, C., Lingam, R., Coad, J., Emond, A. (2012) ' <i>Providing more scaffolding: Parenting a child with DCD, a hidden disability</i> '. <i>Child: Care, Health and Development</i> 38 (6) 829-835	Payne S, Ward G, Turner A, Taylor MC, Bark C (2013) ' <i>The social impact of living with developmental coordination disorder as a teenager</i> '. <i>British Journal of Occupational Therapy</i> 76 (8) 362-369
Clear evidence of study aims? <i>Goal clear?</i> <i>Why important?</i> <i>Relevant?</i>	Goal: to gain in-depth understanding of the personal stories and the experiences of parents parenting young people with DCD Relevance: DCD is a common disorder, but there is limited research in the UK exploring the impact of a child's DCD on family life.	Goal: To investigate the social experience of teenagers living with DCD from their own perspective. Relevance: common condition with evidence of negative impact in adulthood. Little known about impact of DCD in adolescence.
Is qualitative method appropriate? <i>Aim to interpret/illuminate actions or experiences?</i> <i>Does methodology address research goal?</i>	Yes – to gain a deeper understanding of parents' experience ,	Yes – to explore the lived experience.
Is research design appropriate?	Yes Qualitative study, semi-structured interviews & thematic analysis	Use of IPA & interviews justified
Was the recruitment strategy appropriate? <i>How were participants selected?</i> <i>Why were they appropriate to access knowledge sought?</i> <i>Discussion about recruitment issues</i>	Purposive sample of parents of 15 children diagnosed with DCD Recruitment drawn from a clinical population. Purposive sampling to ensure variation in age, sex, area of residence and presence of associated difficulties 11 mothers, 4 fathers of 4 girls and 7 boys aged 11-15 years. MABC score below 5 th percentile	Purposive sampling via a national support group Appropriate sample size – 6 participants. 5 boys, 1 girl aged 13 living with DCD: slight gender imbalance. Participants willing to share experiences & had previously been diagnosed with DCD/dyspraxia by a medical doctor (not confirmed by researcher – weakness of study) No discussion re potential bias associated with recruiting via support group
Was data collected in a way that addressed the research issues? <i>Appropriate setting?</i> <i>Data collection method clear?</i> <i>Methods justified?</i> <i>Methods modified? Why & how?</i> <i>Is form of data clear?</i> <i>Is data saturation discussed?</i>	Individual interviews, carried out in the family home (1 exception) No information about questions provided – how they were developed or modifications made Data saturation achieved	Yes – individual interviews in familiar environment Data collection method described & justified Reference group involved in identifying relevant & meaningful interview topics Data saturation not mentioned. Limited member checking
Has the relationship between researcher & participants been considered? <i>Researcher role</i> <i>How researcher responded to events as they occurred.</i>	No information provided on researcher role or influence on findings.	Lead author/researcher is an occupational therapist - role of researcher's values & beliefs as a necessary part of the reflexive investigation articulated. Role of reference group & their influence on identification of themes discussed.

Ethical issues addressed?	Ethical approval process reported	Approval via university procedures Informed consent procedures described
Data analysis sufficiently rigorous? <i>Process described?</i> <i>How were themes derived?</i> <i>How was data chosen to demonstrate analysis?</i> <i>Enough data to support findings?</i> <i>Considers contradictory findings?</i> <i>Bias considered?</i>	Coding process described 2 researchers coded transcripts Emergent themes discussed with wider team Parents consulted about study findings and model Several quotes used to illustrate each finding Contradictory findings included Bias associated with location of study & limited ethnic mix of sample reported	Iterative process of analysis described Involvement of reference group in analysis detailed Themes selected for their richness and meaning Quotes used to illustrate findings Influence of researcher & reference group on prioritization of themes acknowledged.
Clear statement of findings? <i>Evidence for & against?</i> <i>Credibility discussed?</i> <i>Findings discussed in relation to research question?</i>	3 themes identified Parents consulted about study findings, but how this was achieved if not explained No further discussion re credibility of findings Findings linked to research question	Social impact of DCD on relationships with peers, parents & siblings articulated. Findings related to research question Differences in experience highlighted Limited evidence for impact of gender on social participation recognised Limited member checking Involvement of reference group enhanced findings by offering 'insiders' perspective' during analysis
How valuable is the research? <i>Contribution to knowledge apparent?</i> <i>Areas for further research identified?</i> <i>Transferable findings?</i>	Study adds to limited evidence of impact of DCD on family life and parents. Findings support those of other researchers investigating the impact of disability on parents Implications for awareness-raising among professionals; pathways to diagnosis; & need for parents to act as advocates highlighted. UK sample, although limited to one geographical region	Study offers new insights into the social challenges experienced by teenagers with DCD – little previous evidence from teenagers' own perspective Areas for further research identified Limitations of study that might impact on transferability noted

Paper details	Rodger, S., Mandich, A. (2005) <i>'Getting the run around: accessing services for children with developmental co-ordination disorder'</i> <u>Child: Care, Health and Development</u> 31 (4) 449-457	Stephenson E, Chesson R (2008) <i>'Always the guiding hand: parents' accounts of the long-term implications of DCD for their children & families'</i> . <u>Child: Care, health & development</u> 34 (3) 335-343
Clear evidence of study aims? Goal clear? Why important? Relevant?	Goal: to gain a deeper understanding of the experience of parents of children with DCD in accessing services Relevance: need to alert health professionals to the importance of heeding parents' concerns in order to improve service provision.	Goal: To explore parents' perceptions of the long-term implications of DCD for their child & family Relevance: Little research into this area, despite high prevalence & increased referrals to OT services
Is qualitative method appropriate? Aim to interpret/illuminate actions or experiences? Does methodology address research goal?	Yes – to explore parents' perceptions of the experience of accessing services	Mixed methods study. Qualitative interviews appropriate to explore specific issues in more depth & capture real life examples
Is research design appropriate?	Qualitative phenomenological study Interviews with one or both parents of 10 children	Yes - Case study design with qualitative & quantitative components Questionnaires & interviews
Was the recruitment strategy appropriate? How were participants selected? Why were they appropriate to access knowledge sought? Discussion about recruitment issues	Parents of 10 children with DCD attending a Canadian clinic for therapy Criterion sampling – parents had accessed therapy services All YP scored below 15 th percentile MABC & movement difficulties affected day to day activities	Clinical sample – families whose children had attended clinic 6 years previously 51% response rate – more boys than girls. Most non-respondents had less severe DCD so findings may not reflect their concerns Follow-up interviews with 12 volunteer families – were their features different to those who did not volunteer for interview? YP with additional diagnoses not excluded to reflect heterogeneity of clinical sample
Was data collected in a way that addressed the research issues? Appropriate setting? Data collection method clear? Methods justified? Methods modified? Why & how? Is form of data clear? Is data saturation discussed?	Interviews conducted in therapy centre – may have biased findings (although themes illustrate the difficulties of accessing services so setting may not had had significant impact) Broad interview questions provided No discussion re data saturation	Interview questions guided by questionnaire findings & questions arising from previous studies. Interviews at home or in clinic No discussion re data saturation
Has the relationship between researcher & participants been considered? Researcher role How researcher	Interviews conducted by treating therapist – authors argue this enhances likelihood of honest & accurate responses (fear of affecting future intervention not discussed)	Acknowledgement that participants may have been motivated to participate by desire for more professional contact– previous contact with OT had been fleeting No discussion as to how the

<i>responded to events as they occurred.</i>		researcher/clinical roles were managed
Ethical issues addressed?	Ethical approval process not described (independent clinic so may not be required) No discussion re ethical issues	Ethical approval by Research Ethics Committee
Data analysis sufficiently rigorous? <i>Process described?</i> <i>How were themes derived?</i> <i>How was data chosen to demonstrate analysis?</i> <i>Enough data to support findings?</i> <i>Considers contradictory findings?</i> <i>Bias considered?</i>	Trustworthiness discussed Member-checking of transcripts Some parents reviewed emerging themes from their interviews Open-ended questions 2 researchers audited transcripts & findings. Quotes used to illustrate each theme and subtheme Bias not discussed Limited presentation of contradictory findings	Questionnaires coded Interviews coded & themes identified – limited info about process or analytical framework for analysis provided. Quotes used to illustrate themes Contradictory findings presented Bias – presence of continuing problems may have encouraged some parents to participate in study. Parental perspective gathered, not that of young people directly
Clear statement of findings? <i>Evidence for & against?</i> <i>Credibility discussed?</i> <i>Findings discussed in relation to research question?</i>	Findings presented under 2 broad headings: 'participation problems experienced by YP with DCD' and 'seeking services for children with DCD: the journey'. 2 nd theme most relevant to research question. Unclear which quotes are from which parent (some parents might be over-represented)	6 themes identified Some differences in responses highlighted No discussion re credibility of findings, although limitations of clinical sample mentioned. Findings relation to research question
How valuable is the research? <i>Contribution to knowledge apparent?</i> <i>Areas for further research identified?</i> <i>Transferable findings?</i>	Supports findings of previous studies (e.g. Ahern 2000; Stephenson et al 2008; Missiuna et al 2006) indicating that parents have difficulty accessing services or securing a diagnosis. Study adds to understanding about the impact of the journey on families & therefore on children with DCD. Study highlights primary and secondary impact of motor difficulties on daily activities & on family life. Study reinforces need for professionals to elicit and address parents' concerns as part of therapy services.	Findings support findings of previous research – persistence of motor and secondary social/emotional problems Impact of continuing difficulties on family identified Higher incidence of bullying compared to other studies Implications for OT suggested Need for further research with YP as respondents

Quantitative studies

Paper details	Cairney J, Hay J, Faught B, Corna L, Flouris A (2006) 'Developmental Coordination Disorder, age and play: a test of the divergence in activity-deficit with age hypothesis' <u>Adapted Physical Activity Quarterly</u> 23 261-276	Cantell M, Smyth M, Ahonen T (1994) 'Clumsiness in adolescence: educational, motor & social outcomes of motor delay detected at 5 years' <u>Adapted Physical Activity Quarterly</u> 11 115-129
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study to test whether the activity-deficit experienced by yp with p-DCD increased with age. Issue is of concern because of the risk to physical health & well-being in adulthood associated with reduced physical activity in childhood YP with pDCD aged 9-14 years Not an intervention study, so minimal risk to participation.	What are the educational, motor & social outcomes for children diagnosed as clumsy at age 5 years, at age 15? Outcomes = some Movement ABC tasks, other motor tasks, school records, WISC, self-perception scale for adolescents & an interview re pastimes & hobbies Cohort study. No intervention, so no risk to participation
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Sample drawn from 5 Canadian primary school & represented 12.4% of yp aged 9-14 years. Sample biased towards white, middle class participants, although cohort was multi-raced YP with medical conditions & known learning disorders excluded from participation/analysis N=12 in older group of yp with DCD 9-14 years) Mean age for group: 11.46 years More girls (25) than boys (19) with p-DCD in total sample	115 children identified from population screening with delayed motor development aged 5 years (9 excluded because of low IQ or diagnosis of CP). 40 controls. Children re-tested aged 7, 9, & 11 years. At age 15, 81/106 subjects & 34/40 controls were re-tested. No info about attrition reasons/profiles provided. Gender profile of subject and control groups not provided. Some YP from DCD group attended special school, unlike controls.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Order of testing meant researchers with blind to results of motor test Participation Questionnaire – designed by researchers & used in previous studies. Good evidence of construct validity & correlations with teacher report of activity (0.62) provided. Test-retest reliability reported as 0.81. BOTMP-Short Form administered – validity/reliability data reported elsewhere. Standard score below 38 (10 th percentile) chosen to classify pDCD.	Some motor tasks taken from experimental version of Movement ABC (upper age limit of this test was later reduced to 12 years, so validity for YP aged 15 is questioned) Other tasks based on adult neurological testing – may affect test sensitivity Comparison of achievement of YP attending traditional and special schools is difficult because of differences in reporting – results may therefore over-estimate differences Not all subjects completed interview because of time – no discussion re profile of those who did/did not participate in interview. Assessors blind to previous categorization
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Gender & age considered Presence of ADHD not considered Severity of motor difficulties not considered	Difference in IQ scores between control and clumsy groups & impact on educational outcomes discussed. Differences between YP with different IQ re perceptions of scholastic competence considered Gender, over-lapping diagnosis, impact of

		any interventions not discussed.
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	Cross-sectional study design. No loss to follow-up	8 years between assessments.
What are the results? <i>How precise are they?</i> <i>Strength of findings/associations</i>	Teenagers with pDCD participate in fewer organised (mean 2.83 activity units compared to mean 4.98 in control group) & free play (11.42 compared to 13.72) activities than peers However, there was no evidence of an age by DCD interaction with organised or free play activities i.e. even though DCD group participate in fewer activities, the deficit does not increase/change with age Statistical power to detect a DCD by age interaction is however limited by small sample size – standard errors are too large.	46% YP with motor delays aged 5 still have motor problems aged 15. Measurements taken aged 5 did not clearly distinguish between clumsy and intermediate group aged 15, suggesting heterogeneity in developmental trajectories YP who were clumsy had lower IQs than intermediate or control groups – difference apparent at age 7, but did not increase over 8 years. Clumsy children differed in performance of physical school activities & spare time interests compared to controls & intermediate group. Social & educational outcomes for intermediate group were poorer than for controls, even though some of their motor difficulties had resolved.
Are the results believable?	Study results limited by small sample size & limitations of Participation Questionnaire (self-report measures can over-estimate participation, unclear whether ‘activity units’ are comparable) As the study has a cohort design, findings may reflect differences in the cohort rather than true differences associated with age.	Conclusion that YP with persistent motor difficulties, or motor difficulties associated with lower IQ have negative consequences for educational outcomes has some face validity.
Can results be applied to a local population?	Canadian study – need to consider cultural differences/values when applying findings to local population.	Finnish study – different educational system to UK Cultural differences in performance expectations/attitude towards & opportunity for physical activity
How do the results compare to other studies?	Findings similar to those of Bouffard et al (1996) who examined physical activity participation in younger children. However, findings do not reflect those studies that include older yp (e.g. Barnett et al (2013), suggesting that differences in physical activity participation may not emerge until late adolescence.	Findings support previous studies suggesting that educational & social outcomes are poorer for YP with persistent motor difficulties. Also that motor difficulties do not persist for all YP.
What are the study implications for practice?	Findings indicate that YP with DCD participate in fewer physical activities than peers. Possible impact on long term physical health & wellbeing indicates need to promote participation in physical activities that are a good match for a young person’s capabilities & interests.	Need to consider educational & social implications for those whose motor difficulties are less severe and who may therefore not be a priority for intervention.

Paper details	Cantell M, Smyth M, Ahonen T (2003) <i>'Two distinct pathways for DCD: persistence & resolution'</i> <u>Human Movement Science</u> 22 413-431	Cantell M, Crawford S, Doyle-Baker P (2008) <i>'Physical fitness & health indices in children, adolescents & adults with high or low motor competence'</i> <u>Human Movement Science</u> 27 344-362
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Are young people aged 17 with DCD/mild coordination difficulties/controls distinguishable in terms of their perceptual-motor performance/IQ/educational choices/perceptions of athletic & scholastic competence/identity development? Cohort study, no intervention was given therefore no risks to participation.	Study to determine whether children, adolescents & adults with high/low motor competence had different fitness levels; & whether low motor competence was associated with health factors linked to obesity & cardiovascular disease Issue is of concern as people with DCD are thought to be at increased risk of poor physical fitness in adulthood YP with motor difficulties aged 8-9, 17-18 & 20-60 years. Cross-sectional study design. No intervention so minimal risk to participation.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	65 adolescents selected from an initial sample of 115 children tested at age 15 and who were previously identified from population screening aged 5 years. Participants had equal chance of being selected. Group membership was defined by test scores at age 15. No indication in this paper as to whether other conditions were excluded More boys than girls in each group, but DCD group had 9 girls and 13 boys i.e. more girls than research suggests for gender ratios	Participants recruited via advertisements at a children's hospital & a university (self-referral). 3 age groups: <ul style="list-style-type: none"> 8-9 (13 males, 16 females) 17-18 (20 males, 16 females) 20-60 (21 males, 24 females) Higher number of females than prevalence data suggests
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	8/19 motor tasks used at age 15 were re-administered aged 17 – chosen for their predictive power (not all tasks re-administered) Tasks taken from standardised tests – reliability of parts (rather than whole) of tests not discussed. Some tests had adult (rather than child) norms & may therefore be less sensitive WISC used aged 15, WAIS aged 17 (different tests of intelligence may yield different results) Ceiling effects due to age/motivation for tasks which may be too old/young acknowledged.	DCDQ completed by participants or parents: adequate validity & reliability Experimental version of MABC age band 4 administered to 2 older age groups– age bands changed in final version of MABC-2 WISC/WAIS as a measure of intelligence Series of objective fitness tests (although many required a degree of motor coordination that was compromised in people with poor motor skills) Unclear whether fitness assessors were aware of movement assessment results.
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Lower intelligence scores for DCD group as a confounding factor acknowledged & addressed. No indication of presence/absence of overlapping conditions or whether	Age & gender considered in analysis No indication whether participants had received therapy/intervention Weekly energy expenditure determined & considered in analysis

	<p>participants received motor intervention between assessments.</p> <p>Change in IQ test from WISC to WAIS identified as a factor leading to lower scores at age 17</p> <p>Gender influence on perceptions of physical competence discussed.</p>	
<p>Was follow-up of subjects:</p> <p><i>Compete enough?</i></p> <p><i>Long enough?</i></p>	Cross-sectional study design at age 15 & 17	Cross-sectional study design
<p>What are the results?</p> <p><i>How precise are they?</i></p> <p><i>Strength of findings/associations</i></p>	<p>YP with DCD performed persistently poorly on tests of motor function compared to controls & intermediate group (effect size 0.15-0.48 depending on task)</p> <p>DCD has lowest estimated IQ, but others didn't differ significantly.</p> <p>DCD group had lower self-perception than controls for scholastic competence, & lower than controls & intermediate group for athletic competence</p>	<p>Individuals with low motor competence had compromised health-related fitness compared to peers ie. Low endurance, flexibility & strength</p> <p>Low motor competence was associated with higher BMI/being overweight or obese (p+0.02)</p> <p>Motor skills & static balance were significant predictors of BMI</p>
<p>Are the results believable?</p>	<p>Face validity – no surprises</p> <p>Findings support previous research indicating developmental change in YP with DCD in adolescence, but not in a homogenous pattern</p>	<p>Population were self-referrals so may not be representative of all people with low motor competence (although effect size suggests bias had little impact on findings)</p> <p>Fitness was measured by tasks that themselves required motor competence, so at-risk population was disadvantaged</p>
<p>Can results be applied to a local population?</p>	<p>Finnish study – different educational system to UK</p> <p>Cultural differences in performance expectations/attitude towards & opportunity for physical activity</p>	<p>Canadian study. Possible cultural differences in value placed on & access to physical activity.</p>
<p>How do the results compare to other studies?</p>	<p>Findings are consistent with previous studies indicating that the educational & social outcome is encouraging for some YP with DCD.</p> <p>However, performance is individual & those with persistent severe difficulties have poorer outcomes.</p>	<p>Findings are consistent with studies by Cairney et al (2005), Coverdale et al (2012) & Wagner et al (2011) indicating that those with low motor competence are at risk of high BMI & poor physical fitness in adolescence/adulthood</p>
<p>What are the study implications for practice?</p>	<p>Evidence for intervention to support motor development in childhood to minimise negative life experiences that impact on educational & social outcomes</p>	<p>YP with DCD are at risk of reduced physical fitness which has long term implications for their general health</p> <p>Need for well-planned early intervention programmes to break the negative participation cycle & under-activity in teenagers with DCD.</p>

Paper details	Chirico D, O’Leary D, Ciarney J, Haluka K, Coverdale N, Klentrou P, Hay J, Faught B (2012) ‘ <i>Longitudinal assessment of left ventricular structure and function in adolescents with DCD</i> ’ <u>Research in Developmental Disabilities</u> 33 717-725	Coverdale N, O’Leary D, Faught B, Chirico D, Hay J, Cairney J (2012) ‘ <i>Baroflex sensitivity is reduced in adolescents with probable DCD</i> ’ <u>Research in Developmental Disabilities</u> 33 251-257
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study aimed to investigate 1) whether adolescents with p-DCD demonstrated elevated left ventricular mass & cardiac output over a 3 year period & 2) factors most strongly associated with elevated left ventricular mass & cardiac output in YP with DCD Follow-up study over 3 years, no intervention	Study testing the relationship between baroreflex sensitivity & DCD in adolescents Issue is of concern as young people with DCD are less fit and physically active & have increased body fat compared to their physically able peers.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Participants drawn from a large scale population study Aged 12 at start of study, 14 at follow-up ‘Probable DCD’ (p-DCD) identified by BOTMP-SF screening, confirmed by MABC2 at/below 16 th percentile 63/198 eligible (p-DCD) students agreed to participate – no information about those who choose not to participate provided. Appropriate gender ratio Unclear whether YP with over-lapping conditions were excluded	Participants drawn from a large scale population study 63 YP aged 13 years who scored below 10 th percentile on BOTMP-SF aged 10 & who agreed to participate in further study. Appropriate gender ratio for p-DCD group (14:7 boys:girls) Participants grouped into those who scored at/below 5 th percentile (p-DCD), 6-16 th percentile (suspect DCD or spDCD) & typically developing (TD) if above the 16 th percentile on the MABC. Impact of motor difficulties on ADL not assessed, hence p-DCD description. No indication whether co-occurring difficulties (including ADHGD) were identified/excluded.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Objective measures & procedures for measuring cardiac dimensions, body mass, fat mass, body mass index & aerobic fitness described Same measures for all participants Unclear whether assessors were blind to participants’ DCD status	Objective measures of height, weight, body composition, blood pressure, heart rate, & aerobic fitness carried out. Subjective assessment of pubertal maturity Severity of motor difficulties assessed with MABC. All participants completed same assessments in same order. No indication whether assessors were blind to DCD status.
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	No discussion re over-lapping conditions (e.g. hypermobility, ADHD) Gender, height, maturity, body mass considered & accounted for in analysis	Comparison group had lower weight & blood pressure than p-DCD & spDCD groups. Gender, maturation considered in analysis. No discussion re socio-economic/family factors or participation in physical activity which may impact on findings.
Was follow-up of subjects:	Full data available for 33/63 students with p-DCD: no	21 YP from initial sample of 63 did not participate in 2 nd year of lab testing from

<i>Compete enough? Long enough?</i>	explanation provided for reduction in sample size, with exception of attrition due to poor cardiac ultrasound images which meant they were unsuitable for analysis.	which these findings are drawn. No discussion re characteristics of those who declined the invitation to continue.
<i>What are the results?</i> <i>How precise are they?</i> <i>Strength of findings/associations</i>	YP with p-DCD demonstrated elevated cardiac output compared to controls, and was significant associated with elevated fat mass in p-DCD group ($p<0.001$) P-DCD group demonstrated elevated left ventricular mass which was significantly & independently associated with cardiac output and fat mass.	P-DCD & spDCD groups had increased percentage body fat compared to TD group ($p<0.001$ for each comparison) TD had higher relative peak aerobic power than spDCD & p-DCD groups ($p<0.001$ for each comparison) Baroreflex sensitivity was lower in the p-DCD group compared to the TD group ($p=0.049$) – this was mainly attributed to higher percentage body fat in those with pDCD.
<i>Are the results believable?</i>	Important study with small but ‘difficult to reach’ sample. Clear description of procedures for study & analysis suggest results are believable, but further study is indicated.	Findings compare favourably to other studies
<i>Can results be applied to a local population?</i>	Canadian population study. Possible cultural differences between UK & Canada could impact on YP’s perceptions of physical competence & therefore their motivation to engage in physical activity. Difference between fitness of YP with DCD 7 peers may be greater in Canada than in UK.	Canadian study. Cultural differences (e.g. value placed on physical activity, ease of access) might impact on transferability of findings.
<i>How do the results compare to other studies?</i>	Consistent with findings from series of studies by Cairney et al, indicating tendency towards obesity in YP with DCD & impact on cardiorespiratory fitness	Findings support previous work by Cairney et al (e.g. 2011) indicating increased risk of obesity/poor cardiorespiratory fitness in YP with DCD.
<i>What are the study implications for practice?</i>	Findings suggest increased risk of hypertrophy in adults with DCD as this is associated with higher fat mass/obesity in childhood. Authors suggest need to monitor & improve physical fitness in children with p-DCD to prevent risk of cardiovascular disease in later life.	Baroreflex sensitivity is a risk factor for future cardiovascular disease, therefore there is a need for targeted intervention to improve the cardiovascular health of YP with DCD.

Paper details	De Oliveira R, Wann J (2010) <i>'Integration of dynamic information for visuomotor control in young adults with developmental coordination disorder'</i> <u>Experimental Brain Research</u> 205 387-394	De Oliveira R, Wann J (2011) <i>'Driving skills of young adults with DCD: regulating speed and coping with distractions'</i> <u>Research in Developmental Disabilities</u> 32 1301-1308
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Examining hypothesis that the coordination difficulties of YP with DCD are the result of poor integration of distal preparatory visual information combined with the visual information available during movement execution. Not an intervention study Low risk to participation in a computer simulated driving activity	Experimental study examining the hypothesis that the coordination difficulties of YP with DCD are the result of poor integration of distal preparatory visual info with visual information available during movement execution No intervention. Low risk to participation as the study involved participation in a computer simulated driving activity.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	40 YP aged 15-27 years recruited from a previous study. 20 YP had previously scored at or below 15 th percentile on MABC: on re-testing 14 had persistent motor difficulties. Motor performance improved in remaining 6 who were considered to have 'atypical development' (AT). Age matched controls. Unclear whether co-occurring ADHD was excluded (may have been part of original study protocol but not reported here).	23 YP aged 16-22 years 11 previously diagnosed with DCD aged 10, and who achieved a score at/below 15 th percentile on MABC when re-tested. Suggestion that participants were drawn from an earlier study – no further information provided. Similar number of males/females – more females than prevalence studies indicated.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Driving simulator & virtual steering procedures developed for this study. Properties of simulator and objective measurement calculations described Participants provided with practice opportunities before trial started. No risk of researcher bias in collecting data as this was gathered electronically	Properties of driving simulator described. Virtual steering procedures developed for this study. Objective measurements captured by computer. Same procedures for all participants – practice opportunity provided
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Severity/persistence of motor difficulties considered in analysis Participants had little or no previous driving experience Diagnosis of attention difficulties not considered.	Participants had little or no previous driving experience (matched by controls) No indication that attention difficulties were considered/screened No indication whether participants with DCD had received therapy/intervention
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	On-off assessment, so no losses to follow-up or incomplete data.	No incomplete data
What are the results? <i>How precise are they?</i> <i>Strength of findings/associations</i>	YP with DCD and AD were slower & more variable in their steering control than control group, but group differences dissipated when	YP with DCD used significantly more adjustments to the steering wheel & showed larger variance in heading when turning bends, but not when driving along

	<p>visual cues highlighting directional changes necessary within the next 500m were provided.</p> <p>Surprisingly, when given a map of the full course layout, the performance of YP with DCD decreased.</p> <p>Group differences reported for variables from $p < .001$ – $p < 0.5$</p>	<p>straight roads compared to controls</p> <p>Average speed was similar to controls, but may have been too quick for DCD group to steer effectively</p> <p>DCD group noticed pedestrians as quickly as controls, but were slower in reacting to them.</p>
<i>Are the results believable?</i>	<p>Finding that response times were slower & more variable in DCD group are consistent with clinical observations.</p> <p>Surprising finding that DCD group found it hard to integrate fast visual information & longer term information with physical action, but could work with either separately.</p>	<p>Findings support reports by adults with DCD that they find driving difficult (e.g. Kirby, Sugden & Edwards 2011)</p>
<i>Can results be applied to a local population?</i>	UK study	UK study
<i>How do the results compare to other studies?</i>	<p>Supports findings of earlier research indicating that movements of YP with DCD are slower & more variable than controls (e.g. Lord & Hulme 1988).</p> <p>Also supports more recent research by Wilmot & Wann (2008) indicating that YP with DCD have difficulty using advance information for motion direction.</p>	<p>Emerging area of research, but findings support limited evidence that people with DCD struggles to integrate visual info and motor responses to successfully perform steering actions (de Oliveira & Wann 2010)</p>
<i>What are the study implications for practice?</i>	<p>Suggestion that people with DCD are unable to establish an appropriate perceptual-motor map when 2 streams of visual info are provided across different temporal frames has implications for driving instructors</p> <p>The suboptimal integration of near & far visual info is an area worthy of further study</p>	<p>Poorer steering control & slower reactions to hazards may have implications for safety of drivers with DCD.</p>

Paper details	De Oliveira R, Wann J (2012) <i>'Driving skills of young adults with developmental coordination disorder: maintaining control & avoiding hazards'</i> Human Movement Science 31 721-729	Eggleston M, Hanger N, Frampton C, Watkins W (2012) <i>'Coordination difficulties & self-esteem: a review & findings for a New Zealand survey'</i> Australian Occupational Therapy Journal 59 456-462
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Examines the hypothesis that people with DCD would have poorer performance in terms of steering control, speed & reactions to pedestrians compared to controls. No intervention. Low risk to participation as the study involved participation in a computer simulated driving activity.	What is the self-esteem of children & adolescents with DCD? Issue is of concern because YP with poor motor coordination have consistently been found to have lower self-esteem in relation to physical activity & athletic competence.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	26 males, mean age 17.4 years including: - 8 YP previously diagnosed with DCD (aged 10) who scored at or below 15 th percentile on retesting - 5 YP previously diagnosed with DCD but who achieved a score at/above 16 th percentile on retesting (atypical development – 'AD' group) 13 controls matched for age, gender, computer game use & driving experience	Postal questionnaire sent to 843 members of the New Zealand support group for people with dyspraxia (including parents, professionals & adults) Some impact of recruiting through support group – members are unlikely to represent all parents of those affected by a condition (may include more with more severe difficulties) 167 returned (20% response) of which 75 were valid 77% eligible respondents were male (higher than gender prevalence studies suggest) Mean age 13.6 years Co-occurrence was: 50% dyslexia, 15% anxiety disorder, 10% ADHD, 10% ASD, 9% learning difficulty
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Properties of driving simulator described Virtual steering procedures developed for this study Computer captured responses Practice opportunity provided Same procedure for all participants	<i>Children's Self-Concept Scale</i> (Piers & Herzberg 20012) completed by YP – no reliability/validity data provided Findings not compared to normative standards as control group was not available Demographic & other info provided by parents
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Severity/persistence of motor difficulties considered Participants had little or no previous driving experience (matched by controls) No indication that attention difficulties were considered/screened Participants & controls matched for previous gaming experience	YP with existing diagnosis of ASD included as parents with ASD as a primary diagnosis are more likely to join an ASD support group. Excluding these YP did not affect the findings Authors suggest presence of co-existing conditions as a potential confounding factor in relation to self-esteem Authors acknowledge that parents who belong to a support group are unlikely to represent the general population or even all parents of those with dyspraxia.

<i>Was follow-up of subjects: Compete enough? Long enough?</i>	No reports of missing data	One-off study
<i>What are the results? How precise are they? Strength of findings/associations</i>	YP with DCD showed larger heading variance than controls ($p=.05$) or AD ($p=.01$) group YP with DCD made more steering adjustments on bends than controls ($p<.05$) Tendency for DCD group to drive more slowly on straight roads than controls ($p=.07$) DCD group detected the virtual crossing pedestrians as well as controls, but were slower to react to them ($p<.01$) Severity of coordination difficulties correlates positively with persistence of symptoms & impacts on reaction times to hazards.	Scores for YP with DCD indicated low self-esteem in relation to physical appearance & attributes; intellectual & school status; & popularity. Low levels of global self-esteem overall. Lower self-esteem was not associated with freedom from anxiety
<i>Are the results believable?</i>	Findings support reports by adults with DCD that they find driving difficult (e.g. Kirby, Sugden & Edwards 2011)	Sample is not representative of all YP with DCD, although findings are similar to those of others studies. Sample may have more severe motor difficulties. Lack of association between global self-esteem & anxiety is surprising and may reflect poor test sensitivity.
<i>Can results be applied to a local population?</i>	UK study	New Zealand study. Different school system and cultural values may affect self-esteem differently to UK.
<i>How do the results compare to other studies?</i>	Limited research in this area. Findings support those of Wilkie et al (2008) suggesting that steering inaccuracy may relate to ineffective gaze strategy	Lower co-occurrence of ADHD compared to other studies (e.g. Gillberg 1989) may reflect different diagnostic pathways in NZ or sample selection bias Poorer perceptions of physical appearance, popularity & intellectual status reflect findings of other studies e.g. Skinner & Piek 2001
<i>What are the study implications for practice?</i>	People with DCD may benefit from fixing on consecutive points around a bend to help with steering Driving speed of YP with DCD may be too quick for them to respond safely to visual information including hazards	Movement difficulties increase the risk of low global self-esteem. Professionals need to take into account each individual's unique profile of strengths, difficulties & interests to enhance participation & self-esteem. Need to look for co-existing conditions as their presence is likely.

Paper details	Geuze R, Borger H (1993) 'Children who are clumsy: Five years later' <u>Adapted Physical Activity Quarterly</u> 10 1-21	Gillberg I C, Gillberg C (1989) 'Children with preschool minor neurodevelopmental disorders iv: behaviour & school achievement at age 13' <u>Developmental Medicine & Child Neurology</u> 31 3-13
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Do children identified as clumsy aged 6-12 years still have motor problems 5 years later? If such problems are measurable, are they perceived by parents & teachers? No intervention	Study to examine the behavioural & school outcomes of YP identified with minor neurological dysfunction (with and without ADHD) identified at age 6/7, at age 13. Cohort study. No intervention, so no risk to participation
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	School sample Original sample included 31 clumsy & 31 matched controls selected from sample of primary school children based on teacher opinion & TOMI test results IQ in clumsy group was lower than comparison group, but within normal range Clumsy children with co-occurring diagnosis of hyperactivity (n=6) were excluded from follow-up study. Gender data not presented.	Sample drawn from a population-based study of the perceptual, motor & attentional deficits of children aged 6-7 years. Current study followed-up those YP previously identified with motor perception dysfunction (MPD) & attentional deficit disorder (ADD) at age 13 including: <ul style="list-style-type: none"> - 37 YP with MPD/ADD combined - 5 with MPD only - 10 ADD only - 44 comparisons MPD only group is very small and has more girls than boys 3:2 girls:boys) Other developmental problems (e.g. cerebral palsy) & learning difficulties excluded
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Assessors blind to previous status. TOMI re-administered – 12 year old norms so results may suggest a lack of sensitivity for older YP (under-representation) Experimental version of TOMI with more challenging tasks also administered & standardised against norm sample using standardization strategy for original TOMI. Performance compared against age & sex-matched control for each child.	Standardised rating scales completed by parents, teachers & YP including Rutter questionnaire, Connors questionnaire, Birmleson depression inventory. No reliability/validity data provided.
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	6/31 children with hyperactivity excluded from follow-up No indication that other co-occurring conditions were considered/excluded Some of clumsy group had received physio or OT	Gender considered – no significant impact on findings. Attention considered in study design & analysis Severity of motor/attention difficulties considered in analysis
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	14/25 clumsy children available for follow-up. Attrition due to change of address. I declined to participate. No other info provided about those lost to follow-up provided 5 year follow-up	Explanation of attrition from earlier studies provided. YP with learning difficulties & those originally in comparison group but subsequently identified with mpd/add were excluded

<i>What are the results?</i> <i>How precise are they?</i> <i>Strength of findings/associations</i>	<p>Half of clumsy group scored within normal range at follow-up. Findings may reflect lack of test sensitivity as lower age norms were applied.</p> <p>Problems experienced by remaining 6 children varied</p> <p>Children who were clumsy had more academic problems & lower achievements than controls</p> <p>Teachers indicated more motor, social & behavioural problems than comparison group</p> <p>Ceiling effect of using lower age norms considered – performance on more challenging tasks also assessed.</p>	<p>65% YP with mpd/add had poor school achievement compared to comparison group</p> <p>No significant differences between mpd & comparison group except for more daydreaming by mpd group ($p<0.001$)</p> <p>Parents reported more behavioural problems among mpd/add than comparison group ($p<0.001$)</p> <p>Agreement between parents & teacher rating of behaviour was not good</p> <p>16% YP in mpd/add group had abnormal depression scores compared to 7% in comparison group & none in either mpd or add groups</p> <p>85% YP with severe mpd/add had severe behavioural problems at age 13</p> <p>Yp with mpd/add were poorer at spelling ($p<0.01$) & reading ($p<0.01$) than comparison group</p> <p>Writing was poorest amongst YP with severe mpd/add ($p<0.001$)</p> <p>2/5 yp in mpd-only group had poor academic outcomes</p> <p>Diagnosis of psychiatric abnormality at age 6, regardless of concomitant mpd/add meant worse behavioural outcomes than those without</p> <p>Conduct disorders were less prevalent than 'emotional' disorders (withdrawal, daydreaming) among mpd/add group</p>
<i>Are the results believable?</i>	Non-clinical sample	<p>Study is based on a population sample (no clinical intervention)S=</p> <p>Numbers of YP with mpd only are very small, so findings should be interpreted with caution</p>
<i>Can results be applied to a local population?</i>	<p>Dutch population so different culture.</p> <p>Study over 20 years old.</p>	Swedish study with very different educational system to UK (no formal education until age 6)
<i>How do the results compare to other studies?</i>	Findings comparable to those of Losse et al (1991) and Gillberg et al (1980) i.e. around 50% yp continue to experience motor difficulties in adolescence; difficulties are heterogeneous & not limited to the motor domain.	<p>Heterogeneity of symptoms & co-occurrence of attention difficulties is reflected in other studies (e.g. Dewey et al 2007)</p> <p>Risk of emotional/behavioural concerns is also consistent with more recent work (eg. Pearasall-Jones 2011)</p>
<i>What are the study implications for practice?</i>	Some children with poor motor coordination aged 7 continue to have difficulties that extend beyond the motor domain 5 years later – intervention may benefit to some to prevent long term adverse consequences.	Combination of mpd & add leads to poorer behavioural, emotional & academic outcomes. Clinicians therefore need to assess for and treat attention difficulties in YP presenting with poor motor coordination.

Paper details	Gillberg I C, Gillberg C, Groth J (1989) 'Children with preschool minor neurodevelopmental disorders v: neurodevelopmental profiles at age 13' <u>Developmental Medicine & Child Neurology</u> 31 14-24	Hellgren L, Gillberg C, Gillberg IC, Enerskog I (1993) 'Children with deficits in attention, motor control & perception (DAMP) almost grown up: General health at 16 years' <u>Developmental Medicine & Child Neurology</u> 35 881-892
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	What happens to YP with deficits in attention, motor control & perception as they get older if no intervention is provided? Cohort study. No intervention, so no risk to participation	What are the physical & psychosocial outcomes of DAMP identified in childhood at age 16 years? Cohort study. No intervention, minimal risk to participation
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Original sample taken from a population screened at age 6 years Sample of 141 children screened age 6-7 <ul style="list-style-type: none"> - 7 with mpd (4 boys, 3 girls): - Further 42 diagnosed with mpd & add combined - 51 controls - 29 excluded for reasons explained More girls in mpd group than prevalence studies indicate (although sample is very small)	Sample drawn from a population-based study of the perceptual, motor & attentional deficits of children aged 6-7 years. A sample of YP were followed-up after 10 years including: <ul style="list-style-type: none"> - 13 with severe mpd/add - 26 moderate mpd/add - 6 mpd - 11 add - 45 comparisons More males than females in each group Cerebral palsy etc & severe learning disabilities excluded
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Neurological assessment comprised a battery of clinical observations, rather than a standardised assessment (not available at the time) Inter-rater reliability reported to be acceptable. However, more points could be 'scored' for fine motor compared to gross motor tasks, meaning a bias towards YP with fine motor difficulties. Subjective assessment of quality of movements Assessors were blind to YP's original diagnoses	Assessors blind to group status. Evaluation included tools used previously – mainly clinical observations (subjective measures). Inter-rater reliability reported for some items. Observations supported by review of medical records
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Family history, perinatal & postnatal concerns, psychosocial factors, minor physical anomalies, EEGs, WISC considered as confounding factors in analysis YP with learning difficulties & additional psychiatric diagnoses were excluded	Gender considered, but numbers of girls too small Pubertal maturity & general health/illness considered
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	16 (14%) eligible YP dropped out of neurological follow-up because they moved away (11/96) or refused to participate (5/96):	10% attrition – moved away or refused to participate.

	<ul style="list-style-type: none"> - 2/7 mpd group (29%) - 5/42 mpd/add group (12%) - 2/12 add group (17%) - 7/51 comparison group (14%) 	
<i>What are the results?</i> <i>How precise are they?</i> <i>Strength of findings/associations</i>	<p>Despite improvements in motor skills, there was still a difference between the motor performance of yp with motor difficulties & those without in around 30% of cases at age 13.</p> <p>There is around a 50% overlap between mpd & add</p> <p>Combination of add & mpd had a negative impact on outcome</p> <p>YP with milder mpd/add had clinically significant behavioural & educational difficulties, even when neurological signs had lessened</p>	<p>Boys aged 16 with DAMP were at increased risk of:</p> <ul style="list-style-type: none"> • Speech & language disorder (p<0.01) • Accidents requiring hospital admission (p<0.01) • Prolonged visual reaction times (p<0.001) • Febrile seizures (p<0.05) • Substance abuse (p<0.05) <p>But some boys did relatively well.</p> <p>Results for mpd-only group were similar to combined mpd/add group, whereas add group were more similar to comparison group. Authors suggest that perceptuo-motor factors are an indicator for poorer general health (but numbers in the study were small)</p>
<i>Are the results believable?</i>	<p>Researchers did not have the advantage of the range of standardised assessments available now. However findings do reflect those observed clinically and reported in more recent studies. In particular, more severe difficulties more likely to persist into adolescence, while milder motor difficulties may resolve.</p>	<p>Researchers did not have the advantage of the range of standardised assessments available now. However findings to reflect those observed clinically and reported in more recent studies. In particular, the impact of combined motor/perceptual/attention difficulties on health and behavioural outcomes.</p>
<i>Can results be applied to a local population?</i>	<p>Swedish population with different education system Old data – social & cultural climate is different now.</p>	<p>Swedish population with different education system Old data – social & cultural climate is different now.</p>
<i>How do the results compare to other studies?</i>	<p>Co-existence of DCD & ADD is reflected in many other studies.</p> <p>Persistence of motor difficulties into adolescence/adulthood is supported by more recent literature (e.g. Kirby et al 2011)</p>	<p>More recent research indicates a link between DCD & speech/language difficulties (e.g. Archibald et al 2008)</p> <p>Parental reports indicate increased risk of accidents (Missiuna 2007)</p>
<i>What are the study implications for practice?</i>	<p>Without intervention, motor difficulties persist into adolescence for some YP.</p> <p>No claims are made regarding the possible impact of intervention for this population.</p>	<p>Suggestion of increased risk of negative social & health outcomes, even when motor difficulties are less severe but particularly when accompanied by poor attention. Need for intervention/support to minimise the risk.</p>

Paper details	Hellgren L, Gillberg C, Gillberg IC (1994) ' <i>Children with deficits in attention, motor control & perception (DAMP) almost grown up: the contribution of various background factors to outcome at age 16 years</i> ' <i>European Child and Adolescent Psychiatry</i> 3 (1) 1-15	Knight E, Henderson S, Losse A, Jongmans M (1992) ' <i>Clumsy at 6 – still clumsy at 16: the educational & social consequences of having motor difficulties in school</i> ' <i>Sport & Physical Activity – Moving towards excellence</i> ed by Williams T, Almond L & Sparkes A (London) 249-259
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study to examine the contribution of different background factors to the 10-year outcome of YP with DAMP diagnosed at 6-7 years. Cohort study. No intervention, so no risk to participation	What are the educational * social consequences of childhood movement difficulties in adolescence? Follow-up school cohort study – no intervention
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Sample drawn from a population-based study of the perceptual, motor & attentional deficits of children aged 6-7 years. A sample of YP were followed-up after 10 years including: - 13 with severe mpd/add - 26 moderate mpd/add - 6 mpd - 11 add - 45 comparisons More males than females in each group	Follow up at age 16 of 15 YP identified by their teachers as having movement difficulties when aged 6 years. Participants had comparable IQ at age 6 years (measure of IQ not described)
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Swedish version of the Personality Disorder Examination (Loranger et al 1987) adapted for use with teenagers. Non-standardised assessment of speech & language, general health & life events Medical records examined Participants completed self-report psychiatric/personality disorder inventory. Researchers did not have access to standardised assessments now available.	TOMI administered at age 16: no discussion re norms (standardised for use up to 11 years of age) Details of neurodevelopmental test not provided School reports rated for 'effort' & 'attainment' using locally devised rating system. Evaluation of behavioural & emotional problems based on researchers' interpretation of school reports Harter Scale of Perceived Competence used to measure different domains of self-concept Adapted questionnaire re school & leisure interests administered, based on previous work by another author.
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Membership of the mpd-only group was less than 10 making statistical analysis of this variable cautions.	IQ comparable at age 6 No discussion re gender, possible occurrence of overlapping conditions, or whether YP had received any intervention.
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	Attrition of 10% from original sample due to house move (5 cases) or refusal to participate (6 cases). Highest percentage drop out was for mpd group (1/7 cases, 14%)	Results for 15/16 YP traced at follow up provided. No details re YP who was not included.
What are the results? <i>How precise are they?</i>	Poorer overall outcome in DAMP group compared to comparison	Clumsy group significantly different to controls (level of different not stated) in

<i>Strength of findings/associations</i>	<p>group</p> <p>Strongest predictor of very poor outcome in mpd/add groups were poor reading skills at age 10 or 13; low performance IQ at age 7; presence of autistic traits age 7; high antisocial & depression scores age 10.</p> <p>However, some individuals with poor outcome risk factors, including delayed early language development, poor performance IQ age 7 & minor neurological dysfunction age 7 had good overall outcomes</p> <p>Overall the strongest predictor of poor outcome was the presence of DAMP.</p>	<p>terms of mean neurodevelopmental test score & TOMI mean score; academic attainment; perceived social, physical & total competence rating; enjoyment of sport & leisure activities.</p>
<i>Are the results believable?</i>	<p>Researchers did not have the advantage of the range of standardised assessments available now. However findings do reflect those observed clinically and reported in more recent studies. In particular, the combination of motor and attention difficulties affects performance outcomes</p>	<p>Case studies provided to support quantitative findings & demonstrate 'real world' impact of motor and associated difficulties</p>
<i>Can results be applied to a local population?</i>	<p>Swedish population with different education system Old data – social & cultural climate is different now.</p>	<p>UK school-based population Old study, so culture & environment has changed</p>
<i>How do the results compare to other studies?</i>	<p>Study findings represent a gloomier picture than some more recent studies, perhaps reflecting the 'natural outcome' if intervention/support is not provided.</p>	<p>Findings present slightly less optimistic outcomes for teenagers with motor difficulties compared to some other studies</p>
<i>What are the study implications for practice?</i>	<p>Combination of poor motor skills, attention difficulties & other factors (delayed language, poor performance IQ) increases the risk of negative outcomes if appropriate support is not provided.</p>	<p>Risk of academic underachievement in YP identified at age 6 with motor difficulties is highlighted</p>

Paper details	Kwan M, Cairney J, Hay J, Faught B (2013) ' <i>Understanding physical activity & motivations for children with DCD: an investigation using the theory of planned behaviour</i> ' <u>Research in Developmental Disabilities</u> 34 3691-3698	Losse A, Henderson S, Elliman D, Hall D, Knight, E, Jongmans M (1991) ' <i>Clumsiness in children – do they grown out of it? A 10 years follow-up study</i> ' <u>Developmental Medicine and Child Neurology</u> 33 55-68
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study examined how variables of the Theory of Planned Behaviour relate to physical activity behaviours assessed by accelerometry between boys with and without DCD.	To evaluate the motor, psychological & educational status of teenagers identified as having poor coordination aged 6 years, at age 16 Follow-up school cohort study: no intervention
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Participants drawn from a large scale population study Sample of 61 boys aged 13-14, including 19 boys with p-DCD Boys only as research indicates that boys with DCD are less likely to participate in physical activity than their peers. p-DCD indicated by MABC score below 16 th percentile. No assessment of impact on daily life activities.	Follow-up of children identified 10 years earlier by teachers as having poor coordination for their age. All original 'clumsy' group traced. One other control found to be 'clumsy' on assessment was also included. 14 boys, 3 girls in 'clumsy' group i.e. fewer girls than current prevalence data suggest Partial data on 2 participants for reasons explained All attending mainstream school
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	'Theory of Planned Behaviour' measure used in previous studies with acceptable internal consistency. Language modifications made following pilot testing. 'Attitude towards physical activity' scale developed based on scale developed by Ajzen (2006) which has acceptable internal consistency <i>Likert</i> scale to gather perceptions of others' attitudes towards physical activity – good internal consistency <i>Intention to perform physical activity</i> measured using items from Ajzen's scale. High internal consistency. <i>Accelerometer</i> plus activity log book used to assess actual time spend in physical activity <i>KBIT-2</i> to assess cognitive function.	Different neuro-developmental tests used for initial & follow-up study Different motor tests administered aged 6 & 16. TOMI standardised test of motor impairment administered age 16, using norms for YP aged 11 years. Other measures (WISC, Perceived Competence Scales) appropriate for use with teenagers. Quality & quantity of data from school records varied so difficult to draw accurate comparisons, Ratings given based on teachers' reports of problems – dependent on teachers' awareness & insight. Interest questionnaire adapted from another study – no info re validity/piloting/modifications made Assessors blind for all tests except 'interests' interview
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	No discussion re over-lapping conditions (e.g. hypermobility, ADHD) Research assistants/assessors blind to participants' DCD status Socio-economic status, IQ, & BMI considered in analysis Authors suggest other salient factors not captured in their study might include birth weight & family factors	YP aged 6 had not been referred for medical or educational assessment Original sample had verbal IQ within average range No info re inclusion/exclusion criteria in original study e.g. co-occurring conditions excluded? Gender not discussed
Was follow-up of subjects:	Cross-sectional study design	All original cases traced Follow-up after 10 years.

<i>Compete enough? Long enough?</i>		
<i>What are the results?</i> <i>How precise are they?</i> <i>Strength of findings/associations</i>	Boys with DD participated in significantly less physical activity per day than controls (accounting for 11% variance) Boys with DCD scores significantly lower in physical activity behaviour ($p < .05$) & cognitions ($p < .05$) compared to controls Boys with DCD reported lower in attitudes ($p < .05$) & perceived behavioural control ($p < .05$) compared to peers No significant differences in mean measures of subjective norms & intentions Attitudes & subjective norms were significantly related to participation in physical activity ($p < .05$) & partially mediated the relationship between p-DCD & participation in moderate to vigorous physical activity.	YP identified as clumsy aged 6 years were still clumsy at age 16 – TOMI results reliably distinguished between clumsy & comparison groups Ceiling effect of motor skills assessment apparent – performance reports suggest an underestimation of qualitative differences in motor performance Clumsy group different to controls in terms of verbal IQ, academic achievement & perceptions of social, physical and overall competence.
<i>Are the results believable?</i>	Consistent with clinical observations that motivation towards physical activity affects participation & is influenced by culture & attitudes of others.	Credibility of findings enhanced as researchers captured the impact of motor difficulties (as well as measuring motor performance) by gathering info from school reports ie. 'real world' impact
<i>Can results be applied to a local population?</i>	Canadian population study. Possible cultural differences between UK & Canada could impact on YP's perceptions of physical competence & therefore their motivation to engage in physical activity. Difference between fitness of YP with DCD 7 peers may be greater in Canada than in UK.	UK population. Old study, so educational/social/economic context has changed
<i>How do the results compare to other studies?</i>	Supports previous findings that boys with DCD are less physically active than peers (e.g. Cairney et al 2005) and perceive themselves to be less physical competent (Cairney et al 2005, Fitzpatrick & Watkinson 2003)	Results consistent with other research indicating that motor difficulties noted in childhood persistent into adolescence for many, but not all YP Findings more adverse than some other studies suggest
<i>What are the study implications for practice?</i>	Deficit in physical activity motivation should be a focus for intervention at school, by therapists & in social/community settings. School PE should be more flexible & adapt to the skills/needs of the individual. Risk to physical health of continued inactivity. Need for interventions targeting perceived approval of influential people & personal evaluations of physical activity in boys with DCD	Minor motor difficulties in childhood persist into adolescence for many YP Difficulties manifest not just in motor domain but in social/behavioural/academic areas too Relationship between severity of coordination problems & other outcomes is complex – environmental factors are likely to have an effect Secondary school heightened existing difficulties & revealed new ones for some YP.

Paper details	Miayara M, Piek J (2006) ' <i>Self-esteem of children & adolescents with physical disabilities: Quantitative evidence from meta-analysis</i> ' <u>Journal of Developmental & Physical Disabilities</u> 18 (3) 219-234	Piek J, Baynam G, Barrett N (2006) ' <i>The relationship between fine & gross motor ability, self-perceptions & self-worth in children and adolescents</i> ' <u>Human Movement Science</u> 25 65-75
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Meta-analysis to examine the effects of minor physical disabilities (mpd) on different domains of self-esteem, & the effect of major physical disabilities on general self-esteem in children & adolescents.	Study examining the impact of fine & gross motor ability on the self-perceptions of children & adolescents No intervention: cross-sectional design
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	1984 YP from 13 studies, of whom 788 were classified with mpd/probable DCD Aged 4-18 years Male = 379 Female = 205	265 yp selected from mainstream schools: 164 aged 7-11 years & 101 aged 12-15 years. Similar no. girls and boys in younger sample but more girls than boys in adolescent sample. Sample drawn from 7 schools – no indication whether they opted to participate, were nominated by teachers, or were randomly selected. Exclusions: intellectual or neurological disability Categorised as with/without DCD by performance on Neuromuscular Development Index No assessment of impact of motor difficulties on academic/daily performance as this 'has been difficult to operationalise'. Justification given that 'applying this criterion detracts from the importance of motor competence in its own right'.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	Unidimensional & global measures of self-worth included Effect size & p-values of group differences calculated	<i>McCarron Assessment of Neuromuscular Development</i> – tool used mainly in Australia where it was developed with local norms <i>Self-perception profiles</i> – separate tools for children & adolescents, but content overlaps and author is the same. American norms, good internal consistency.
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Gender and age groups considered, but small number of studies precluded analysis by these factors Co-existing conditions not accounted for – complex interactions might impact on global & domain-specific self-esteem	Comparison of self-perceptions by age, sex & movement ability. Gender considered in analysis. Differential impact of gross & fine motor difficulties on self-worth examined
Was follow-up of subjects: <i>Compete enough?</i>	n/a	One-off assessment, so no losses to follow-up

<i>Long enough?</i>		
What are the results? <i>How precise are they?</i> <i>Strength of findings/associations</i>	Minor physical disabilities had a high negative impact on athletic competence (effect size 0.78), & a moderate negative effect on self-esteem (0.45), physical appearance (0.49) & social acceptance (0.49). Minor physical disabilities might affect self-esteem of physical appearance, but other factors contribute too e.g. sampling error. Major physical disabilities did not affect general self-esteem as much as minor physical disabilities.	YP with DCD differed from controls in perceptions of athletic & scholastic competence. Poor fine motor ability was associated with lower perceived scholastic competence. In boys with & without DCD, perceived athletic competence related to self-worth. In girls with & without DCD, scholastic competence was related to self-worth; for girls with DCD, athletic competence also affected self-worth suggesting that the psychosocial implications may be more severe for girls with DCD and was equally influenced by poor gross & fine motor skills
Are the results believable?	Heterogeneity of findings in perceived global self-esteem suggests a complex interaction between global self-worth & other self-esteem domains. Variability in findings in perceived global self-worth suggests sample bias, & differences in measurements & sample size between studies.	Link between poor fine motor skills & lower perceived scholastic competence makes sense as handwriting is the means by which learning is demonstrated Link between gross motor ability and athletic competence is reasonable Poorer perceptions of scholastic & athletic competence perhaps reflects a more realistic perception of ability with age
Can results be applied to a local population?	Meta analysis of studies including populations from UK, Canada, Australia & Netherlands.	Australian study – athletic/sports competence is important within this culture
How do the results compare to other studies?	Findings support more recent studies in which YP with mpd rate their physical performance as poor, and lack confidence in their physical appearance & social participation (e.g. Piek et al 2006, Rigoli et al 2012)	Similar findings of poorer perceived competence have been reported elsewhere (Losse et al, Skinner & Piek 2001, Cantell et al) Study did not find perceptions of social acceptance as a significant variable, unlike some other studies.
What are the study implications for practice?	Positive self-concept is linked to better mental health, therefore self-esteem is an important consideration for therapists, Factors such as importance of physical activity, social comparison & internalization of negative feedback affect general self-esteem as well as self-perceived athletic competence.	Need to consider impact of fine or gross motor difficulties, or both, on perceptions of self-worth in order to address motor & psychosocial problems of YP with DCD.

Paper details	Piek J, Rigoli D, Pearsall-Jones J, Martin N, Hay D, Bennett K, Levy F (2007) ' <i>Depressive symptomatology in children and adolescent twins with attention-deficit hyperactivity disorder &/or DCD</i> ' <i>Twin Research & Human Genetics</i> 10 (4) 587-596	Rigoli, D, Piek J, Kane R, Oosterlann J (2012) ' <i>An examination of the relationship between motor coordination & executive functions in adolescents</i> ' <i>Developmental Medicine & Child Neurology</i> 54 1025-1031
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Investigation into the relationship between ADHD, DCD & depression, examining genetic and environmental factors that influence depression. Also to examine the relationship between co-morbid DCD/ADHD & depressive symptoms, as previous studies indicate comorbidity increases the risk for poor psychosocial outcomes in this population. Cohort study. No intervention, minimal risk to participation	Study to examine the relationship between motor coordination & executive functions in adolescents. Although it has been observed that complex cognitive processes affect motor performance, evidence of the relationship between the factors is limited. Not an intervention study, so minimal risk to participation.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Participants selected from a large twin study, mean age 13.2 years Co-twin comparison included: <ul style="list-style-type: none"> 16 pairs of identical twins one with & one without ADHD (12 male, 4 female) 24 pairs of twins, one with & one without DCD (11 male, 13 female) YP taking stimulant medication identified. YP with physical disability, chronic illness or another medical condition excluded. Study group compared with full twin sample, divided by birth order; by diagnosis (ADHD only, DCD only, combined & control)	Adolescents aged 12-16 years recruited from secondary schools through advertisements No discussion re potential bias arising from self-selecting population. 93 participants: <ul style="list-style-type: none"> 38 females 55 males Gender bias towards females 5/93 scored at or below 5 th percentile on MABC-2: 5.4%, similar to prevalence rates previously reported. Minimum verbal comprehension index of 80 (measured by WISC) to exclude general delayed development. Parental report of absence of physical disability, chronic illness, pervasive developmental disorder & neurological disorder.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	<i>Strengths & Weakness of ADHD Symptoms & Normal Behaviour (SWAN)</i> scale (Swanson et al 2001) – good internal reliability reported. <i>DCD-Q</i> (Wilson et al 2000) – good reliability, validity, sensitivity & specificity reported. <i>Twin & sibling Questionnaire</i> (Hartman et al 2001) includes 12 items relating to 'sad affect' which assess depressive symptomatology – acceptable internal reliability	<i>MABC-2</i> –reliability coefficient of 0.80 for total test score & coefficients from 0.73-0.84 for individual component scores <i>WISC-IV</i> – Excellent internal consistency, reliability & validity reported <i>N-Back test</i> of visuo-spatial working – reliability reported as 0.70 – 0.66. <i>NEPSY-II</i> – naming, inhibition & switching subtests used. Adequate to high internal consistency for subtests reported, as well as good content, construct & criterion-related validity <i>SWAN</i> – reported to find similar prevalence of ADHD in the population as found in other studies
Did authors identify all	Non-genetic risk factors explored by	IQ, ADHD, age, gender, socio-economic

confounding factors? Were these accounted for in the research design/analysis?	examining depressive symptomatology in identical twins. Birth order, sex & age considered Birth weight & apgar scores comparable between groups. More girls in the control group – girls tend to have higher levels of depression which might result in underestimation of depressive symptoms among affected groups.	status & verbal ability controlled for.
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	Cross-sectional study Findings suggest full data acquired for all participants.	Cross-sectional study design. No loss to follow-up
What are the results? <i>How precise are they?</i> <i>Strength of findings/associations</i>	Twins with ADHD or DCD only demonstrated higher levels of depressive symptomatology than non-ADHD ($p=0.016$) or non-DCD ($p=0.003$) twin Twins with combined ADHD/DCD had higher levels of depressive symptomatology than DCD-only & ADHD-only groups ($p=0.05$ to $p<0.001$ depending on birth order) Combined group had higher levels of depressive symptomatology than controls ($p<0.001$)	Movement difficulties were associated with a deficit in visuo-spatial memory ($p=0.041$), but not verbal working memory Relationship between both aiming/catching & visuospatial ($p=0.016$), working memory ($p=0.019$) & verbal comprehension ($p<0.001$) identified Teenagers with DCD had slower performance speed on inhibition tasks compared to controls ($p=0.017$) Association between balance & total errors ($p=0.020$) found, suggesting that maintaining posture requires additional attention for YP with poor motor skills
Are the results believable?	ADHD/DCD symptoms assessed by parent report rather than direct assessment Risk of parental bias – twins more similar or more different Life events not explored, but may affect depressive symptomatology	Findings of an association between executive functions & motor difficulties supports clinical observations that difficulties of YP with DCD are not confined to motor skills.
Can results be applied to a local population?	Australian study. Different culture/expectations to UK might impact on experience of depressive symptomatology	Australian study – need to consider cultural differences/values when applying findings to local population.
How do the results compare to other studies?	Other studies identify increased risk of depressive symptoms in yp with ADHD – study adds to the findings by controlling for genetic factors. Finding support previous studies indicating an association between DCD & depressive symptoms (e.g. Sigurdsson et al 2002, Skinner & Piek 2001) Supports studies suggesting poorer outcomes for YP with DCD/ADHD combined (e.g. Gillberg et al 1989)	Findings support studies suggesting a link between executive functions & motor impairment (e.g. Alloway et al 2010, Piek et al 2008). Slower processing speed similar to findings of Querene et al 2008. However, association between balance & inhibition/switching errors is a new & interesting findings.
What are the study implications for practice?	Need to assess for & treat depressive symptoms in YP with DCD as well as their motor difficulties. This is particularly important for YP with DCD/ADHD combined.	Need to assess for executive dysfunctions in adolescents with DCD Need to consider impact of giving attention to postural demands of a task on learning/attention in class.

Paper details	Rigoli, D, Piek J, Kane R (2012) 'Motor coordination & psychosocial correlates in a normative adolescent sample' <i>Pediatrics</i> 129 (4) 2892-2900	Shaffer D, Schonfeld I, O'Connor P, Stokman C, Trautman P, Shafer S, Ng S (1985) 'Neurological soft signs: their relationship to psychiatric disorder & intelligence in childhood & adolescence' <i>Archives of General Psychiatry</i> 42 342-351
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study to examine the relationship between motor coordination & executive functions in an adolescent normative sample. Previous studies reveal a relationship between motor coordination difficulties & emotional function. This study sought to examine whether the association was mediated by self-perceptions in 'typical' adolescents.	To determine the relationship between soft-sign status at age 7 & psychiatric disability, diagnosis & IQ at age 17 No intervention
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Adolescents aged 12-16 years recruited from secondary schools through advertisements No discussion re potential bias arising from self-selecting population. 93 participants: <ul style="list-style-type: none"> • 38 females • 55 males Gender bias towards females 5/93 scored at or below 5 th percentile on MABC-2: 5.4% which is similar to prevalence rates previously reported.	Birth cohort study 63 boys & 26 girls who demonstrated at least 1 neurological soft sign aged 7 years. No neurological disease, IQ within normal range Controls with similar birth date but no soft signs Girls tested 1 year after the boys: 92% boys age 16-18 years, & 87% girls aged 17-18 years on reassessment. Attrition figures provided: greater attrition for girls without soft signs present (81% tested) compared to 90-97% included for all other groups 58 boys (57 controls) & 25 girls (22 controls) followed up aged 17.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	MABC-2 good reliability & validity reported WISC-IV – good internal consistency, reliability & validity reported <i>Strengths & Weakness of ADHD Symptoms & Normal Behaviour</i> – evidence that this test accurately identifies hyperactivity & attention variables in the typical population <i>Mood & Feelings questionnaire</i> - high internal consistency & reliability reported. <i>Spence Children's Anxiety Scale</i> – high internal consistency & strong psychometric properties reported. <i>Self-description questionnaire-II</i> – good internal consistency & validity reported.	Age 7 – blind assessors carried out series of behavioural & neurological assessments. Possible bias towards over-identification of soft signs aged 7 years which researchers regarded as an advantage in this study. Age 17 – semi-structured psychiatric interview using parts of standardised tools. Inter-rated reliability for assigning psychiatric diagnosis established at 79% agreement. Borderline cases reviewed by other researchers. Involvement of several researchers lessened impact of diagnostic views of individuals. Parent interview re demographics, family history, parental history of psychiatric symptoms incorporated the General Well-being scale. Teachers completed Connors questionnaire. Neurological examination

		re-administered age 17 – reliability data provided WAIS IQ test administered (younger version used age 7)
<i>Did authors identify all confounding factors? Were these accounted for in the research design/analysis?</i>	Age, gender, socio-economic status, ADHD symptoms & verbal comprehension considered, but did not significantly correlate with the outcome variables of anxiety & depressive symptoms, so were not included in analysis.	Controls & subjects did not differ in terms of social-economic status, level of maternal education & other factors Gender considered Relationship between IQ and psychiatric disorders considered Impact of family & social disadvantage considered
<i>Was follow-up of subjects: Compete enough? Long enough?</i>	Cross-sectional study	Losses to follow-up & exclusions described. Losses similar for boys/girls & subjects/controls Not all subjects completed IQ assessment (97% boys, 81% girls) because of time factors
<i>What are the results? How precise are they? Strength of findings/associations</i>	Motor coordination has an indirect effect on emotional functioning through perceptions of physical ability, physical appearance, peer relations, parent relations & school competence.	Boys with no soft signs had higher IQ than those with soft signs. Similar trend for girls. More males than females with soft signs aged 7 had psychiatric disorder aged 17 YP with at least 1 soft sign aged 7 (especially poor coordination) were more likely to have an anxiety-withdrawal disorder aged 17 than controls Relationship between soft signs & affective disorder in boys only. Presence of anxiety alongside soft signs age 7 increased risk of anxiety-withdrawal symptoms at age 17
<i>Are the results believable?</i>	Indirect impact of motor difficulties on emotional functioning via self-perceptions reflects clinical observations. In particular, that YP with similar motor ability on formal testing do not always perform/participate in physical activity to the same level.	Non-clinical sample, representative of local population High follow-up rate Blind assessment
<i>Can results be applied to a local population?</i>	Australian study. Cultural differences in opportunity & values need to be considered when applying to UK population.	American study (New York) so culturally different to UK Almost 30 years old, so diagnostic criteria for indicating psychiatric disorder may have changed
<i>How do the results compare to other studies?</i>	Supports findings of Cairney et al (2010), Skinner & Piek (2001) & Piek (2006) indicating a relationship between motor coordination & perceptions of physical ability/appearance, general School & peer relations. Provides support for studies suggesting impact of environmental	More recent studies also identify a link between DCD and anxiety/depression

	more than biological factors on emotional well-being in YP with DCD (Schaffer 1985) (Piek 2010)	
<i>What are the study implications for practice?</i>	Need to be aware of risk of social isolation for YP with motor difficulties who avoid physical activities. Need to assess emotional outcomes in YP with motor difficulties, & also to consider motor difficulties in YP presenting with anxiety disorders. Self-perceived competences highlighted as an area of assessment/support for teenagers with poor motor skills.	Need for awareness and emotional support for YP showing soft signs and anxiety at age 7 years to prevent long term adverse consequences

Paper details	Sigurdsson E, can Os J, Fombonne E (2002) ' <i>Are impaired childhood motor skills a risk factors for adolescent anxiety? Results from the 1958 UK birth cohort & the National Child Development Study</i> ' <u>American Journal of Psychiatry</u> 159 1044-1046	Skinner R, Piek J (2001) ' <i>Psychosocial implications of poor motor coordination in children and adolescents</i> ' <u>Human Movement Science</u> 20 73-94
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Are motor impairments in childhood associated with anxiety in late childhood & adolescence? British survey of YP aged 5-15 years Cohort study. No intervention, minimal risk to participation	Examination of perceived competence & social support & their influence on self-worth & anxiety in children & adolescents with & without DCD. Cross-sectional study design
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Sample of 6850 YP drawn from the National Child Development study of people born between March 3 & 8 1958 YP at risk of motor difficulties identified age 11 & 16, based on reported motor performance: Late to walk; poor hand control reported by teachers, clumsiness (age 7), poor coordination (age 11) 5.7% population met criteria for motor impairment – 8% boys & 3% girls. Figures broadly consistent with recent UK prevalence data	218 participants recruited from mainstream schools in Australia 58 with DCD aged 8-10 - 51 with DCD aged 12-14 - Equivalent no of controls matched for age & gender DCD group scored below 15 th percentile on MABC; controls scored above 50 th Verbal IQ above 80 for all participants Gender bias towards girls
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	'Persistent anxiety' group determined by parental reports of "frequently worrying about things" age 11, & "often worrying about things" at age 16. Subjective measure from parental perspective	<i>State-trait anxiety inventory for children/adults</i> (Spielberger 1983) – adequate reliability & validity <i>Self-perception profile</i> (Harter 1985) <i>Social support scale</i> (Harter 1988) No incomplete data Same measures (adolescent version where appropriate) for all cases Unclear whether test administrators were blind to DCD status
Did authors identify all confounding factors? Were these accounted for in the research design/analysis?	Assessors blind to the purpose of the study IQ not determined, but sample size was large & representative of the population Social class, birth weight, depressive symptoms & contact with mental health services age 16 considered.	IQ addressed Gender bias acknowledged
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	Large birth cohort	Cross-sectional study design
What are the results? <i>How precise are they?</i> <i>Strength of findings/associations</i>	3.4% of whole sample were identified with persistent anxiety aged 11 & 16 years (95% confidence interval 3-3.7). 3.5% of YP in the 'at risk for motor difficulties' group (95% confidence interval 3.1-4) No such effect was evident for girls	Adolescents perceived themselves to have poorer social support & lower global self-worth than controls ($p<0.01$) & younger children Older children were more anxious than younger children ($p<0.01$) YP with DCD overall reported lower

		<p>self-worth, poorer social support & higher levels of anxiety than controls</p> <p>YP with DCD were significantly more anxious than controls (general anxiety, not just situation-specific) ($p < 0.001$)</p> <p>Adolescents with DCD had lower perceived competence for social acceptance, athletic competence & physical appearance compared to controls, but did not report lower perceptions of scholastic competence.</p>
<i>Are the results believable?</i>	<p>Although measures were subjective, sample was large & representative of the population. Findings reported only one part of those collected, therefore no bias caused by awareness of study focus.</p> <p>Link between persistent motor difficulties & anxiety in teenagers is consistent with clinical observations.</p>	<p>Results are consistent with clinical observations in terms of anxiety, physical appearance & athletic competence. Difference between younger children & adolescents perhaps reflects a more realistic appraisal of abilities with age.</p>
<i>Can results be applied to a local population?</i>	<p>UK population, but old data. It could be argued that YP are likely to feel more anxious because of higher performance expectations & social pressures now than in the past.</p>	<p>Australian population. Difference culture & value placed on physical abilities might impact on perceptions of athletic competence compared to UK</p>
<i>How do the results compare to other studies?</i>	<p>Findings support those of Shaffer (1985) & Hellgren (1994) which suggest motor impairment as a risk factor for persistent anxiety in adolescence</p>	<p>Study did not report lower perceptions of scholastic competence among YP with DCD, unlike studies by Losse et al (1991), Geuze & Borger (1993) & Cantell et al (1994). May reflect different IQ between studies & groups.</p> <p>Lower perceptions of social supports similar to findings of Losse et al (1991) who reported less social acceptance/fewer friends than controls.</p> <p>High levels of anxiety among YP with DCD also reported by Sigurdsson et al (2002) & Pratt et al (2011)</p>
<i>What are the study implications for practice?</i>	<p>Is anxiety a secondary manifestation of DCD, or does anxiety arise because YP are unable to participate successfully in activities of childhood? Either way, timely intervention is necessary to minimise risk of anxiety in adolescence.</p>	<p>Social support in adolescence is important</p> <p>Perceptions of competence are affected across a variety of domains, not just athletic competence.</p> <p>Relationship between competence perceptions & self-worth is complex & not just affected by coordination difficulties.</p> <p>Adolescents' perceptions of the support provided by significant others also affects self-worth.</p>

Paper details	Soorani-Lunsing R, Hadders-Algra M, Huisjes H, Touwen B (1994) <i>'Neurobehavioural relationships after the onset of puberty'</i> <u>Developmental Medicine & Child Neurology</u> 36 (4) 334-343	Visser J, Geuze R, Kalverboer A (1998) <i>'The relationship between physical growth, the level of activity & the development of motor skills in adolescence: differences between children with DCD & controls'</i> <u>Human Movement Science</u> 17 573-608
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study to examine whether neuro-behavioural relationships become more explicit after the onset of puberty. Issue is of interest as little consideration has been given to impact of puberty on motor skills previously. Not an intervention study, so minimal risk to participation.	Study examines the relationship between physical growth, motor competence & level of participation in physical activity during the adolescent group spurt. Study also sought to determine whether YP with DCD are more affected by the adolescent growth spurt than YP without coordination difficulties. No intervention. Minimal risk to participation.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Participants drawn from a longitudinal cohort study 185 identified as having mild neurological deficits (mnd) aged 9. 167 had persistent mnd age 12 years. At age 14 years 68 still had mnd (49 boys, 19 girls). Remaining 259 were comparison group (165 boys, 94 girls) 7 boys who had not reached puberty & 2 girls with mild cranial paresis were excluded age 14.	Boys selected from a mainstream school population, representing the range of motor competence: 15 boys with DCD identified by the Groningen Motor Observation scale & confirmed by scores on the MABC below 10 th percentile. 16 controls matched for age who scored above 15 th percentile on MABC. No assessment of impact of coordination difficulties on daily activities reported IQ assumed to be within typical range as all attended mainstream school – not conformed by testing None reported clear signs of neurological disorders – not confirmed by medical exam
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	<i>Neurological assessment</i> comprised a battery of clinical observations, rather than a standardised assessment (not available at the time) <i>Behaviour</i> evaluated by questionnaire completed by parents, teachers, YP & examiner. <i>NPVJ</i> – Dutch juvenile personality questionnaire (Luteijn et al 1989) completed by YP <i>Interview</i> with YP by examiner to elicit child's self-image <i>WISC-R</i> – measure of attention span <i>Dutch IQ test & Beery test</i> of visual motor integration <i>School achievement</i> considered affected if YP was not in appropriate grade for age or attended a special school <i>Psychosocial situation</i> described according to family events	2 ½ year follow-up of boys identified from the population aged 11 ½ years with poor motor coordination. <i>MABC</i> – possible ceiling effect as norms available up to 12 years only. <i>Retrospective analysis of activity levels</i> by parents/boys was limited – only completed by 6 participants & non-standardised questionnaire used. <i>Objective measures of height & weight</i> Assessors not blind to MABC scores
Did authors identify all	Distractibility (hyperactivity)	Impact of physiotherapy intervention &

confounding factors? Were these accounted for in the research design/analysis?	accounted for in analysis. Puberty, socio-economic status, perinatal history & family adversities considered Gender accounted for in analysis	major illness considered in analysis.
Was follow-up of subjects: <i>Compete enough?</i> <i>Long enough?</i>	Exclusion due to immaturity & presence of other conditions described.	2 ½ year follow-up Full set of movement data for all participants
What are the results? <i>How precise are they?</i> <i>Strength of findings/associations</i>	Comparison group at age 12 & 14 showed a significant decrease in attentional problems at home ($p=0.02$) YP with fine motor problems had an increase in troublesome behaviour ($p=0.02$), hyperactivity ($p=0.02$) & concentration problems ($p=0.02$). No other behavioural differences detected in mnd group. Coordination problems of those who moved out of mnd group age 14 were comparable to those of YP who were normal at both age 12 & 14. Choreiform dyskinesia contributed to hyperactivity & troublesome behaviour at school, a poor self-image, concentration problems & school failure YP with mnd were more likely to experience anxiety, affective of antisocial disorder than those without ($p<0.001$) Fine motor & coordination difficulties were related to low IQ, poor cognitive performance (Beery) & school failure.	Boys with DCD perform worse than peers on standardised test of motor control; however, difference between DCD & control groups decreased with age (ceiling effect?) ($p<0.001$) Individuals differed significantly in the rate of improvement in motor skills over time Some YP with DCD have persistently poor motor skills: 66% had continuing motor difficulties at age 14 Performance of controls deteriorated during growth spurt, while performance of DCD group showed continued improvement over time (although few reached normal motor competence).
Are the results believable?	Lack of standardised assessment tools is a weakness of this study.	Interesting – some YP with DCD seem to benefit from the adolescent growth spurt suggesting neurological maturity as a possible explanation for motor difficulties. Finding that YP with DCD differ in terms of motor performance is consistent with clinical observations (heterogeneous profiles of strengths/difficulties)
Can results be applied to a local population?	Dutch study including old data.	Dutch population – education system more similar to UK than Scandinavian system, but cultural differences still exist
How do the results compare to other studies?	Finding that there is a relationship between persistent mnd & cognitive/behavioural problems in adolescence is consistent with findings of Gillberg et al (1989). Low self-esteem among YP with persistent mnd is consistent with findings of other researchers (e.g. Skinner & Piek 2001)	Persistence of motor difficulties was higher in this study compared to some others; however, participants were identified later (aged 11 years) so may have been more severe than participants in studies by Losses (1991), Cantell (1994) & Geuze (1993).

<i>What are the study implications for practice?</i>	Authors suggest that persistent MND is related to behavioural & cognitive problems aged 14 years. Need therefore to follow up YP with persistent motor difficulties into adolescence to monitor/intervene in relation to low self-esteem.	
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Paper details	Wagner M, Kastner J, Petermann F, Jekauc D, Worth A, Bos K (2011) 'The impact of obesity on DCD in adolescence' Research in Developmental Disabilities 32 197-1976	Wilmot K, Wann J (2008) 'The use of predictive information is impaired in the actions of children and young adults with DCD' Experimental Brain Research 191 403-418
Did the study address a clearly focused issue? <i>Population studied</i> <i>Risk factors</i> <i>Outcomes considered</i>	Study to examine the impact of overweight/obesity on DCD in adolescence. Issue is of concern as research indicates that obesity & DCD persist into adolescence for many yp, often co-occur and have long term implications for health & well-being. Cross-sectional study design with participants aged 11 to 16 years. Not an intervention study, so minimal risk to participation.	Study to test the ability of YP with DCD to organise a movement in response to advanced visual information. Computer tasks so little risk to participation.
Were participants recruited in an acceptable way? <i>Representative of defined population?</i> <i>Anything special about the cohort?</i> <i>Everyone included who should have been?</i>	Clinical sample of 99 obese adolescents (52 boys & 47 girls) & 99 normal-weight adolescents matched for age & gender 17 excluded because BMI fell below 97 th percentile at the start of the study. German adaptation of MABC-2 used to determine motor development: typical development (TD) above 15 th percentile, borderline DCD 6-15 th , & severe DCD (sDCD) at or below 5 th percentile. No attempt to measure impact of motor difficulties on daily performance, or intelligence. No evidence that other conditions were excluded.	23 participants previously diagnosed with DCD Aged 6-23 years, divided into age groups including 6 YP with DCD aged 16-23 years MABC score below 10 th percentile Recruited via national support group – no discussion re bias associated with self-selecting population 11/46 people scored 1 SD below mean in IQ tests: 6 in control group & 5 in DCD group (groups therefore relatively evenly matched) Equal males/females in older group – more females than prevalence studies suggest Other medical conditions excluded None had received intervention for DCD DCD & controls similar on performance of form & motion coherence tasks.
Was outcome accurately measured to minimise bias? <i>Subjective/objective measures</i> <i>Measures validated?</i> <i>Reliable system for detecting all cases?</i> <i>Same measurement methods in all groups?</i> <i>Subjects/assessors blind?</i>	MABC-2 reliability/validity data not reported but known to be good. Objective measures of weight/BMI Assessors presumably not blind to participants' group status.	MABC not validated for oldest participants, but all DCD group achieved a score below 10 th percentile suggesting poor motor performance even compared to younger children. Older group may have more severe difficulties, so results might over-estimate significance of the findings. Task presented in a fixed order of increasing challenge. Authors argue this optimises performance of YP with DCD & is therefore the most appropriate method to highlight persistent difficulties Objective, computer-gathered measurements of response time & eye gaze.
Did authors identify all confounding factors? Were these accounted	Chronological age, weight status & gender considered. Impact of co-occurring attention	All participants were right handed ADHD not screened No reference to experience of computer

<i>for in the research design/analysis?</i>	deficits & participation in daily activity not considered. No discussion re possible reasons for obesity which might impact on motor coordination.	games/driving
<i>Was follow-up of subjects: Compete enough? Long enough?</i>	Complete data available for 156 participants (64/82 clinical intervention group & 92/99 controls). Additional pair-wise data available for some data subsets e.g. for manual dexterity tasks.	Cross-sectional study. No indication of incomplete data.
<i>What are the results? How precise are they? Strength of findings/associations</i>	Obese group showed a higher sDCD risk compared to controls ($p<0.01$) Higher sDCD risk for obese subjects in comparison to controls was most pronounced in balance ($p<0.01$) followed by manual dexterity & more likely to be seen in boys ($p<0.1$) Low prevalence of obese girls with sDCD in balance domain.	Individuals with DCD as a whole were as quick to respond and to complete non-cued movements as controls. However, controls showed lower heading error & number of adjustments compared to DCD group. For full cue conditions, DCD group showed an improvement in composite hand score, but no improvement was seen when presented with a partial cue, when presented with limited predictive motion cue information, or when a large number of visual targets were offered. For all cueing conditions, controls showed a lower eye-hand lead compared to individuals with DCD (no age related differences found) Conclusion that DCD group can use predictive motion cues to pre-program movements, but only when a long temporal gap is given between cue offset & target onset.
<i>Are the results believable?</i>	Study confirms clinical observations of a relationship between DCD & obesity. Although study doesn't seek a causal explanation, authors do suggest some possible explanations that are worthy of further investigation.	95% confidence intervals applied. Performance of DCD group fell below that of peers Study offers possible explanation for observed difficulties of YP with DCD who have difficulty making a quick motor response to a visual cue (e.g. reaching to stop an object from falling off the table)
<i>Can results be applied to a local population?</i>	German population. May be cultural differences re access to physical activity/values/motivation compared to UK	Uk sample
<i>How do the results compare to other studies?</i>	Findings support those of Cairney et al (2005, 2010) of an increased risk of overweight/obesity in yp with DCD.	Findings support those of Mon-Williams et al (2005) suggesting advance information helps YP to plan a movement before a response is required. Also supports Mandich et al (2003) - YP with DCD find it hard to modify a planned movement.
<i>What are the study implications for practice?</i>	Need for interventions focusing on balance & manual dexterity in addition to obesity prevention measures in children with DCD to minimise risk of sDCD in adolescence	YP with DCD had difficulty using predictive motion cues in a rapid task requiring a shorter preparation time e.g. catching a ball, stopping a cup from tipping over.

Scoping Review

Paper details	Camden, C., Wilson, B., Kirby, K., Missiuna, C. (2015) 'Best practice principles for management of children with DCD: results of a scoping review' <u>Child: Care, Health and Development</u> 41 (1) 147-159 (e-print ahead of publication)
Did the review address a clearly focused issue? Purpose/objective(s) clearly defined? Is the value clear?	Goal: to identify the principles that should guide best practice and service delivery for children with DCD. Relevance: DCD is a prevalent health condition, but most literature focuses on measurement of impairment and description of intervention approaches. Purpose of this review is to 'map' information available to inform intervention & service delivery
Is the process for identifying relevant studies appropriate? Clear search strategy? Explicit inclusion/exclusion criteria? Length of time taken to conduct the review? Number of reviewers? Was the methodological quality of the study assessed?	Review adopted the framework developed by Leva et al (2010) Search strategy described – database search plus contact with DCD experts in UK/Canada to sources additional service delivery protocols Flow of information diagram (PRISMA) not included Eligibility criteria included 1 reviewer who discussed questionable articles with 2 others Quality of articles not assessed
Is the data clearly charted? How many reviewers involved in data extraction? Use of a standardized form? Number of articles included? Rigour demonstrated?	2 researchers independently extracted data using agreed criteria/pro-forma Studies characterised according to type of evidence (expert opinion, results from an empirical study, description or current services delivery, review of the literature) 31 articles included, describing 21 unique projects One reviewer checked documents to ensure rigour in the utilization of literature to support statements (no details provided)
What are the results? Is a narrative summary provided? Formal qualitative analysis? Meta-analysis?	37 statements of best practice principles identified and grouped into 2 main themes 17-29 references provide support for each statement Descriptive, qualitative analysis of each theme and principles within them provided.
Are the result believable? Any bias associated with review commissioners? Limitations reported?	Identified principles support focus on integrating child/families views into practice; need to optimize outcomes through population-based interventions; & need for clear, multi-agency pathways to identify & support YP with DCD. Limitations of review include possibility of missed references; & possibility that reviewers differed in perceptions of 'best practice'
Evidence of stakeholder consultation in the review? Assisting with keyword selection? Interpretation of findings? Input into report?	No
Implications for practice	Principles offer guidance to help improve service delivery for YP with DCD so that it is accessible and responsive to children's needs. Review indicates areas for future research & development of innovative management approaches

Appendix D: Research Reference Group Information

Reference Group advertisement

What is it like to be a teenager with dyspraxia?

Recruiting people with dyspraxia aged 16-30 years to help with a research project

I am planning a project to find out what it is like to be a teenager with dyspraxia living in the UK. The project will involve me carrying out a series of three interviews (over two years) with 10 teenagers who will be aged 13 at the start of the study.

To make sure that I am asking the right sort of questions and that my interpretation of the findings is accurate, I am looking to recruit a "**research reference group**". This will be made up of around 6 older teenagers/young adults with dyspraxia. We will meet twice a year at a central location. During the meetings we will develop some interview questions, and then later on we will discuss my analysis of the findings to see if it makes sense.

The purpose of the study is to find out what sort of things teenagers with dyspraxia like doing, what things are difficult and how teenagers think dyspraxia affects their lives. This will help organisations such as the Dyspraxia Foundation, teachers and other professionals to understand what is important to teenagers who have dyspraxia so that they can provide better information and support in the future.

Your involvement in this project will include:

- Attending 7 meetings over the course of three years. The first meeting will take place on Saturday 28th November 2010. The next meeting will take place in May 2010. The final meeting will take place in November 2012. You don't have to commit to being involved all the way through the study but a commitment to at least the first two meetings would be appreciated.
- Meetings will be arranged at a central venue and close to public transport links. Reasonable travel expenses will be paid and refreshments will be provided.
- You will have the opportunity to help present the findings of the study if you so wish. This might include helping to write articles for journals and magazines and co-presenting at conferences and events. However you don't have to do this if you don't want to!



WHAT IS IT LIKE TO BE A TEENAGER WITH DYSPRAXIA?

To volunteer to be part of the research reference group please contact:

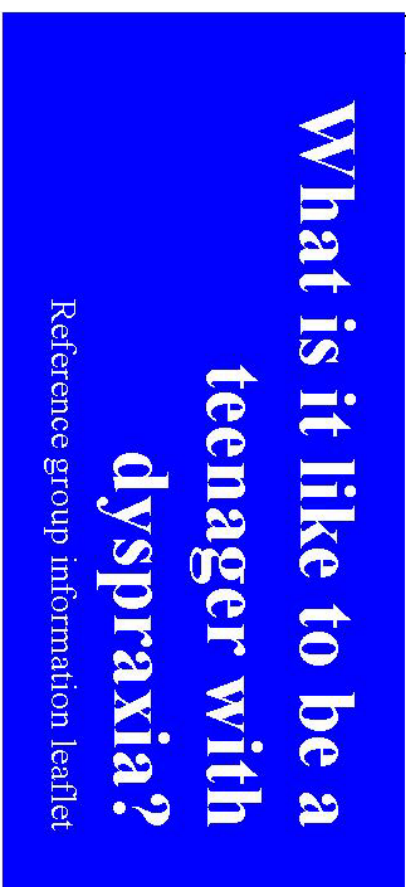
Sally Payne—Researcher
Dyspraxia Foundation

8 West Alley
Hitchin
Herts
SG5 1EG

Phone: 01462 454986

E-mail: [teenresearch@
dyspraxiafoundation.org.uk](mailto:teenresearch@dyspraxiafoundation.org.uk)

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The unabridged version of the thesis can be viewed in
the Lanchester Library Coventry University.



What is it like to be a teenager with dyspraxia? Information about the project

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be viewed in the Lanchester Library Coventry University.

You are being invited to become a member of a research reference group. To help you decide whether or not to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if anything is unclear or if you would like more information. You will be asked to give your consent to participate in the project, so please take time to consider whether or not you would like to take part.

Purpose of the project

Most of the research into dyspraxia focuses on younger children and very little is known about what happens to people with dyspraxia as they grow older. The purpose of this project is to find out what it is like to be a teenager with dyspraxia living in the UK. The information gathered through this project will help organisations such as the Dyspraxia Foundation, teachers and health care professionals to understand what is important to teenagers with dyspraxia so that they can provide better information and support in the future.

Purpose of the Research Reference Group

The research reference group will be made up of six older teenagers and young adults who have dyspraxia. The group will meet to help develop interview questions that cover areas that may be relevant to teenagers with dyspraxia and to ensure that their wording is acceptable. You will also be asked to use your experience and understanding of living with dyspraxia to provide feedback on the researcher's analysis and interpretation of the findings. We hope that involving people with dyspraxia in

the research process will enhance the credibility of the research by ensuring it is relevant to those who will benefit. We also hope that you might choose to help share the findings as we believe this will increase the likelihood of changes being made as a result.

Do I have to take part in the project?

Taking part in the project is voluntary. If you would like to participate then you will be asked to sign a consent form. We will give you a copy of this information sheet and the consent form to keep. If you do decide to take part you can still withdraw from the project at any time without giving a reason for doing so.

What will I need to do? Where will this take place?

You will be asked to attend a total of seven meetings over the course of three years. Meetings will take place in November and May, with the first meeting occurring on Saturday 28th November 2009. During the November meetings the group will help to develop suitable interview questions. During the May meetings the group will provide feedback on the researchers' analysis and interpretation of the findings. You don't have to be involved all the way through the study but a commitment to attend at least the first two meetings would be preferred.

If you decide to participate you will be asked to complete a Contact Information Sheet and a consent form. The researcher will use these contact details to communicate with potential reference group members and to identify a suitable meeting place. Reasonable transport costs to

meetings will be paid and refreshments will be provided.

What are the possible risks from taking part?

There are no specific risks from taking part in the project. However sensitive issues may be raised during the meetings that cause members to relive their own previous and possibly distressing experiences. The researcher is an experienced clinician who is used to dealing with situations when people become upset. Contact details for relevant counselling and support services will be provided for members who need or request them after the group sessions.

What are the possible benefits of taking part?

We hope that the findings of this project will be used to help organisations such as the Dyspraxia Foundation, teachers and health care professionals to develop new support materials and information for teenagers with dyspraxia. As members of the reference group you may also benefit from the experience of being involved in carrying out a research project and sharing the findings afterwards.

Confidentiality - who will know that I am taking part in this project?

No-one apart from the researcher and other members of the group will know that you are involved in the research project unless you choose to tell them. Members of the group will be asked to ensure that any issues raised during the meetings remain confidential. The meetings will be audio taped so that the researcher doesn't have to take notes during the meetings but the tapes will be erased once they have been written up. No names or identifying

information will be used when reporting the study findings without the express permission of those concerned. However, some general information about the membership of the reference group will be described.

What will happen to the results of the project?

Each summer the researcher will write a report which will be presented at the Dyspraxia Foundation AGM, put onto the Dyspraxia Foundation website and printed in the autumn newsletter. It is hoped that this information will help the Dyspraxia Foundation to develop more appropriate resources to support teenagers with dyspraxia. An analysis of the information gathered will also form the basis of the researcher's PhD thesis and may be published in medical journals and conferences.

Who is organising and funding the research?

This project is being supported by the Dyspraxia Foundation and the principle researcher is working towards a PhD at Coventry University.

Who has reviewed the project?

This project has been approved by the Coventry University Research Ethics Panel and by the Dyspraxia Foundation Medical Panel.

What do I do now?

Thank you for considering becoming a member of the Research Reference Group. If you agree to participate please complete the Research Reference Group Contact Information Sheet and consent form and return these to:

Teenage research project coordinator
Dyspraxia Foundation
8 West Alley
Hitchin
Herts
SG5 1EG
Email: teenresearch@dyspraxiafoundation.org.uk

Information about the researcher

My name is Sally Payne and I have been an occupational therapist for 20 years. In the early 1990's I met through my work a number of young people who went on to receive a diagnosis of dyspraxia. I particularly enjoyed working with these children and families because I realised I could make a difference. As time has gone on I have become increasingly aware of the challenges faced by teenagers with the condition. However I am aware that teenagers with dyspraxia cannot always access health services, and that the services that do exist may not provide the support and information that teenagers want or need. I was introduced to the Dyspraxia Trust (as it was then) many years ago by the mother of a child I was working with. I became a Trustee of the Dyspraxia Foundation in 2005 and had the great honour taking over as Chair of the Foundation in 2007. I believe that the information we will gather through this study will help the Dyspraxia Foundation and other organisations to develop better resources and support to help teenagers with dyspraxia. Thank you for considering becoming a member of the research reference group.

If you would like further information please contact:

Sally Payne, Researcher
Dyspraxia Foundation,
8 West Alley,
Hitchin,
Herts,
SG5 1EG
Email: teenresearch@dyspraxiafoundation.org.uk
Tel: 01462 454986



Reference Group meeting plan

Reference Group Meeting Agenda November 2011

Welcome

Some people who have come along to these meetings before - a couple of new faces
Plan – to give some background to the project, explain what I hope to gain this afternoon then some introductions.

Personal introduction

- Research lead – organising and doing interviews
- Student at Coventry University
- Occupational Therapist
- Trustee of Dyspraxia Foundation

Not getting paid – just really interested in dyspraxia and want to help make a difference

Description of research & its purpose

(Copies of information leaflet)

Aim: To find out what it is like to be a teenager with dyspraxia

Want to do this to help the Dyspraxia Foundation and other organisations to understand what is important to teenagers, so that they can provide better support and information in the future.

Rather than ask adults or professionals, I have been speaking to young people themselves

- Last year I spoke to 6 teenagers with dyspraxia aged 13 and this February I carried out interviews with 5 x 14-year olds.
- For the last bit of the project will be carrying out interviews with young people with dyspraxia aged 15 years next February

Today I need your help to:

- Make sure I'm asking the right questions
- Help me think about how to make the young people feel safe enough to answer the questions honestly

Recording

Use recorders

Make some notes to help me remember later. OK?

Confidentiality

Any private things that come up in conversation today we shouldn't discuss outside this meeting.

- Respect each other's privacy

Although I will be talking about this group when I write up the research, I won't use any names or reveal any information that will identify members of the group without asking you first.

OK?

Sensitive issues

Some of the things we might talk about could remind you of your own, perhaps difficult experiences.

- If I see that you are a bit uncomfortable about where the conversation is going I will check to see if you are OK to carry on.
- If you just want to sit back for a bit, if you want to leave the room or get a drink or something, that's fine.
- If there's anything you want to discuss or go over outside of the meeting let me know. I'm happy to talk through issues afterwards or to direct you to other support organisations that may be able to help. I don't want people to go away from this meeting feeling upset or distressed.

Consent forms

You've all signed consent forms to join this group. Are you all happy to carry on? Any other questions before I turn the machine on?

While you are talking I will make some notes that might help us to come up with some questions.

Tell us a bit about yourselves

- Who you are
- What you do
- Why you are interested in this research

Findings from previous interviews:

I think it might be worth sharing some of the main things that have come out of the previous interviews to see if you think I should ask more questions about these.

- **Diagnosis** – Starting to see a pattern of folks not really understanding what dyspraxia is & trying to work out how it affects them. When you were 15, what stage were you at in terms of understanding dyspraxia? How can I explore that with my participants?
- **Supports** – people are telling me that the help offered to them at school isn't necessarily the help they need. What questions could I ask to explore this a bit more?
- **Social networks** – people tell me different things about the way that their friends and family support them and whether this is helpful or not. Is this something I should ask more about?
- **Emotional impact** – I want to find out a bit more about the emotional impact of having dyspraxia, for example feeling stressed and anxious, pressure on self to do well, talking about dyspraxia (disability?). How might I ask about this in a sensitive way?

Let's think about what else was going on when you were 15.

- What was going on for you at school? – exams, revision
- Social life – meeting new people, interests, activities
- Future plans – did these affect your motivation for certain activities?
- Is there anything else you remember from that time that I should ask about?

Have you any suggestions about ways to make the interviewees feel safe enough to talk about their experiences?

The plan

I will write up the questions and will send these to you by email for checking.

I will plan another date to get together in May/June when I've done the interviews so we can have a look at what the young people have said.

Then if we can I'd like to meet again to talk about what I've found from all the interviews together and to decide how we are going to share this information so that others can learn from it.

- Any thoughts about this?
- 29th November meeting

Expenses

Any other questions?

Thank you so much for your help.

Safe journey home

Appendix E: Participant information

Participant recruitment advertisement

RESEARCH PARTICIPANTS WANTED!

What is it like to be a teenager with dyspraxia?

RESEARCH PARTICIPANTS WANTED!

To help other teenagers by sharing
your story please contact

Sally Payne—Researcher

Dyspraxia Foundation

8 West Alley

Hitchin

Herts

SG5 1EG

Phone: 01462 454986

E-mail: [teenresearch@
dyspraxiafoundation.org.uk](mailto:teenresearch@dyspraxiafoundation.org.uk)

I am planning a project to find out what it is like to be a teenager with dyspraxia living in the UK. I am looking for 10 young people who will be **aged 13 in January 2010** to take part in three interviews (over two years) to tell me what life is like for you. You don't have to have a birthday in January but do need to be 13 at the time of the first interview. You will also need to have a diagnosis of dyspraxia (you can have other diagnoses too, but dyspraxia must be your main difficulty).

My plan is to interview you again when you are 14 and 15 years old to see if different things matter to you at different ages.

I want to find out what sort of things you like doing, what things you find difficult and how you think dyspraxia affects your life. This will help the Dyspraxia Foundation, teachers and other people to understand what is important to teenagers who have dyspraxia so that we can provide better information and support in the future.

Your involvement in this project will include:

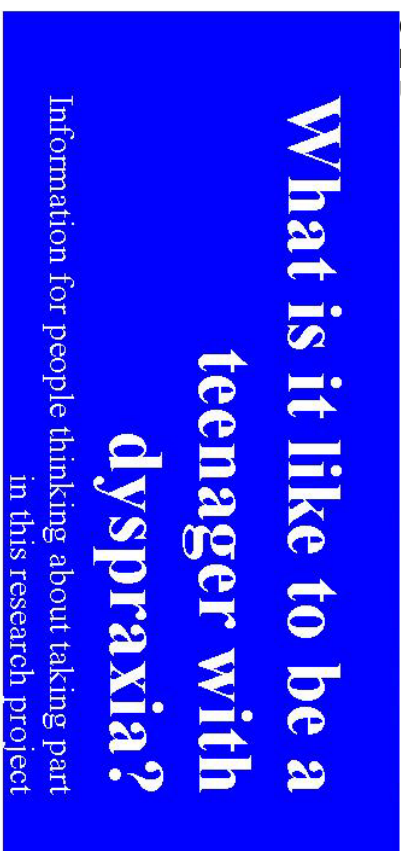
- Participation in three confidential interviews with an experienced occupational therapist during January or February in 2010, 2011 and 2012.
- Interviews will take place at your house (or somewhere else chosen by you) at a time that is convenient

Your parents will need to agree that you can be a part of this study, but they won't be involved in the interviews.

After I have looked at what you have told me a group of older teenagers with dyspraxia will help me to make sense of all the information that I have gathered. I will send you a summary of the things that are most frequently mentioned during the interviews in the summer after each set of interviews.



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What is it like to be a teenager with dyspraxia? Information about the project

This item has been removed due to 3rd Party Copyright. The unabridged version of the thesis can be viewed in the Lanchester Library Coventry University.

You are being invited to take part in a research project. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if anything is unclear or if you would like more information.

Purpose of the project

The purpose of the project is to find out what it is like to be a teenager with dyspraxia living in the UK. We want to find out what sort of things you like doing and how you think dyspraxia affects your life. This will help the Dyspraxia Foundation, teachers and other people to understand what is important to teenagers with dyspraxia so that they can provide better information and support in the future.

Do I have to take part?

No – taking part is up to you. If you do decide to take part, you and your parents will be asked to sign a form. We will give you a copy of this information sheet and the form to keep. If you decide to take part we can take a break during the interview whenever you want to and you don't have to do the whole interview. We would prefer it if you were able to participate in all 3 interviews, but if this is not possible that is OK. We will still be able to use the information you have given us previously.

What will I need to do? Where will this take place?

We ask that you participate in a total of three interviews with the researcher at your home (or somewhere else that you choose). Interviews will take place with the same researcher each year and your parents won't be involved in the discussion. The first interview will take place in January 2010 (when you are 13) and the other interviews will take place in January 2011 (when you are 14) and January 2012 (when you are 15). The researcher will ask you questions about your life, the things that you like doing and the things that you find difficult. Each interview will be tape recorded and will last around 1 hour. Afterwards the researcher will send you a summary of the main things that you have talked about. You will be able to contact the researcher again by phone or email if there is anything else you would like to add.

Is there anything to be worried about if I take part?

We are aware that we might touch on sensitive issues during the interview. If you do not want to answer certain questions, that is fine and you can finish the interview at any time you wish. At the start of each interview the researcher will provide you with contact details for some organisations you can call if you want to talk about your worries with someone not involved in the project.

Who will know I am taking part in the project?

All the information that is collected during the project will remain confidential and tapes and notes from the interviews will be kept in a safe, lockable place. Once each interview has been typed up, any identifying information (such as the name of your school or friends) will be changed and the tape will be wiped clean. Only the researcher will see the written-up interview. However, the notes that are sent to you after each interview will be shown to a group of older teenagers with dyspraxia. This group will help the researcher to make sense of the things that matter to you and the other teenagers in the project. However, they won't be told who you are and your name will not be used in any of the reports that are written about the project.

The researcher will not talk to anyone you know about what you have said unless you talk about the risk of someone being harmed. In this case the researcher will talk with you first about what could be done to help.

What will happen to all this information when the project is over?

By the time the project is finished (July 2013) all of the interviewed tapes will have been wiped clean. The researcher will keep the notes made after each interview, but these won't have any identifying information on them.

What will happen to the results of the project?

In the summer after each set of interviews the researcher will write a report that will be presented at the Dyspraxia Foundation Annual General Meeting. The report will also be put onto the Dyspraxia Foundation website and published in the autumn edition of Dyspraxia News. The results may also be published in medical journals or meetings but you will not be identified by name.

Who is organising and funding the research?

This project is being supported by the Dyspraxia Foundation and the researcher is working towards a research degree at Coventry University.

Who has reviewed the project?

Before a research project goes ahead it needs to be checked to make sure that it is fair. This project has been approved by the Coventry University Research Ethics Panel and by the Dyspraxia Foundation Medical Panel.

What do I do now?

Thank you for thinking about taking part in this project. If you agree to participate please complete the consent form and return this, together with the form completed by your parents to:

Teenage research project coordinator
Dyspraxia Foundation
8 West Alley
Hitchin
Herts
SG5 1EG
Email: teenresearch@dyspraxiafoundation.org.uk



If you would like further information please contact:

Sally Payne, Researcher
Dyspraxia Foundation,
8 West Alley,
Hitchin,
Herts,
SG5 1EG
Tel: 01462 454986

Participant Consent Form

What is it like to be a teenager with dyspraxia?

Participant Consent Form

	Please initial
I confirm that I have read and understood the Participant Information Sheet (version 1.0 dated 8.9.09) for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	
I understand that if I do withdraw then information gathered in interviews that have already taken place will be used as part of the study findings.	
I agree to take part in this study.	

Name of participant:

Date:

Signature:

Name of person taking consent: Sally Payne

Date:

Signature:

Spring 2010

How is life experienced by teenagers with dyspraxia?

Interview Schedule

(Bring: hard copies of the Information for parent/participants & consent forms)

Before starting the interview

Hello, my name is Sally and I'm a researcher from the Dyspraxia Foundation and I'm also doing a research degree at Coventry University. I'm working on a project to find out what it is like to be a teenager with dyspraxia. I think you've already seen some information about the project, but I've brought an extra colour copy for you to keep anyway.

It's really important for the Dyspraxia Foundation to find out what sort of things teenagers with dyspraxia like doing, and how dyspraxia affects your lives. This will help the Foundation to tell other people like teachers and therapists what matters to teenagers so that they can provide better information and support for people like you in the future.

Confidentiality

I am a volunteer for the Dyspraxia Foundation but I don't know anything about your family, school or any of the other people that you might have seen because of your dyspraxia. So I hope you'll feel OK about saying whatever you think.

What you say to me will be kept private. I won't tell anyone what you say, including your parents. But, if you tell me something that suggests that you are another person are in real danger of serious harm then I will ask you if you are going to tell somebody about this. If you decide not to tell anyone but I think there's a real serious risk of harm, then I will have to speak to someone who may then take action. I would only do this in a really serious case - like if you told me that someone had made a real threat to hurt you for example. Is that OK?

Recording

I'm using a recorder to help me with this work so that I can type up the conversation and analyse it later. No recording or typed up notes will have anybody's names on them.

I may also make some notes during our talk to help me check things off as we cover them and to make sure I've given you an opportunity to talk about all of the things that you might think are important.

Consent

If all of that is OK then I've brought an agreement form that I'd like to show you. It just says that we promise to handle information about you very very carefully and that people's names won't be used. I'd like you to sign it if you think it's OK, then I'll sign it as part of the agreement is from me as the researcher

or

I've got a copy of the agreement form that you have signed. It just says that we promise to handle information about you very very carefully and that people's names won't be used. Now I will sign the form as part of the agreement is from me as the researcher. Is that OK?

Is there anything else you want to ask before I turn the machine on?

Begin Interview (turn machine on)

Introduction

Can I start by asking you to tell me a bit about yourself and your family.

- Have you got any brothers or sisters?
- Who do you live with in your house? (Check if spend time with another parent)
- Do your mum and dad both work (if appropriate)
- (Check details if either go away to school or spend time with other parent during week/weekends)

Diagnosis

Perhaps we can talk a bit about your dyspraxia

- Can you remember how you found out that you had dyspraxia?

(Ask about who told them, if they remember going to see a specialist, how they felt about being given the diagnosis, what they were told about it)

- How do you feel about having dyspraxia?

(Do they tell people about it, have they looked for information about it etc)

- How do you think your family (mum/dad/siblings) feel about your dyspraxia? Does the way they deal with dyspraxia affect how you feel about yourself?

(Get a feel for whether they are supportive/dismissive/over-protective)

- Does anyone else in your family have dyspraxia?

(Get a feel for whether they see this as positive, or whether there are any tensions)

- Have you had any special help outside of school (therapy) for your dyspraxia?

How was this therapy described to you? Did people say it would be helpful?

What did/do you think about it?

What was/is good or not so good about it?

Do you think that support was geared towards the things that were important to you?

School

Let's talk a bit about your school now.

- Tell me a bit about the type of school that you go to

(Day/boarding/comprehensive/independent/specialist/single sex)

- How would you describe your experiences at school?

Would you say that you enjoy school?

Which subjects do you like doing?

Which subjects are more difficult?

(Explore any reasons why these are more difficult e.g. involve drawing/lots of writing/handling tools/noisy class/require sporting skills etc)

- Do you have any special help or support at school?
How do you feel about that support?
Is it helpful?
Do you think there another way the school could give you the help you need?

- Is there anything that makes you particularly stressed at school?
(Time management, organisation, social isolation etc)

- Do you think that the teachers at you school understand about dyspraxia?
(Do staff have appropriate expectations, are they flexible about the approaches they use etc)

- What about the other pupils? Do they understand about dyspraxia?
(Look for examples, have they had any information about dyspraxia, bullying?)

Friends/Social

Tell me about your friends.

- Would you say you have a best friend or are you part of a group?

- How would you describe your friends?

(Look for adjectives - weak, supportive, dysfunctional, mainstream etc. Are they "neuro-diverse" too?)

- Is there anything in particular that brings your social group together?
(interested in computers/socially isolated crowd etc)

- Would you say your social group understand your dyspraxia?
Are your friends supportive?

- Would you say you like doing the same kind of things as (or share similar interests with) other people in your year group?
(Sports/drinking/music)

How do you see yourself in comparison to other people of your age?
(Look for pressure to conform/fit in)

- Is there a group of people (community) that you feel more comfortable with, either in school or out of school?
What is it about that group that makes you feel comfortable do you think?
(Is this a group for children with dyspraxia, an organised group such as Scouts etc?)

Leisure

- Tell me what you like to do when you're not at school (Is there anything else you like to do when you're not at school)

(Look for participation in clubs, hobbies, physical activities etc)

- What is it about those activities that you enjoy? What do you get out of them?

Independence

- Is there anything about looking after yourself at home that you would like to tell me about?

(Self-care issues, personal appearance)

- Do you go out by yourself or with friends?

(Look for managing public transport, handing money etc)

- Are there any skills that you think you might need in the future? Are you getting help to develop them now?

(Cooking, driving, shopping etc)

Emotional well-being

Is there anything else that helps you to feel good about yourself?

Other comments?

Are there any other things that you wanted to say about your experience that I haven't already asked you about?

Close

Thank you very much for your time! Now I've got to go away and do some hard work myself. I'm going to type up our conversation and then I will boil it down to get to the main things that seemed to matter to you. In a few weeks' time I'll send you back the summary sheet so you can check it and let me know if I've missed anything out, or have got something wrong. When I've done this with all the teenagers that I'm speaking to I will look at everything that everyone has said to try to find out what really is important to you all. I'm also then going to talk to some older teenagers with dyspraxia to see if what I've said makes sense to them. Then the older teenagers and I will write an article for the Dyspraxia Foundation newsletter and we might also present it at a conference. We'll make sure you get a copy of the article too.

OK, I think we are done here. Thank you again for talking to me and I'll be in touch again soon.

Appendix F: Findings and analysis

Extract from interview 13 (Spring 2012) illustrating process of analysis

Emergent theme	Original transcript	Exploratory comments
Increasing expectations with age	In year 7, 8 and 9 it was a bit more kind of, like it was a bit, it's not as serious obviously as GCSE's 'cos these are really important now, but I did feel in Year 7 all they know was it was a lot more, I felt it was a lot more kind of like relaxed and stuff, and like at a <u>slower pace</u> , and that then like no-one, <u>it's like dyspraxia wasn't really a bit, it was, it was obviously a thing in like DT and stuff, then the lessons that I enjoyed like history and geography and French and stuff, it wasn't a big thing</u>	Temporal issue – pressure increases with age. Pace & expectations increase Variable impact – doesn't affect all lessons all of the time Biggest impact on practical subjects
Increased pace/expectations/challenge		Lower school – more practical subjects, slower pace, wider range of 'normal'
Practical impact	Right, so it was not of an issue in the practical subjects?	
Variable impact	Yeah, in the <u>practical subjects which I did, it was a lot more of an issue</u> , but now obviously <u>I've dropped them</u> it's not really and the school have given me like good support and stuff.	Upper school – opportunity to 'drop' subjects, increased pace & effort, difficulty with simple tasks more obvious, making choices about support
Making choices	OK	
My difference is different to your difference	Only one thing, they wanted to, we got some like Special Needs suite thing called *** and he wanted to like put me in there, but then I, <u>I wasn't really sure</u> because the first time I went in there like they were doing stuff which I was like, Obviously like I know they've got kids with Special Needs and they were doing stuff, like people with this calculator and stuff, like learning to count to ten and stuff. I mean it's not something that, <u>I don't wanna sound rude but I can like do that, I don't need help with that</u> , and they I didn't think it was very like, <u>I wasn't really you know, suited to that</u> , 'cos like I wanted to like, <u>I wanted just to be kind of normal, but then they were kind of like taking me out of that</u> to be like, <u>I know they were trying to help, but I just didn't I didn't really think it helped.</u>	Uncertain about whether SEN provision is appropriate Supported geared towards learning, not organisation/practical subjects Cognitively able, but unable to demonstrate Help offered isn't what he needs My difference is different to your difference Wanting to fit in , be 'normal' Doesn't 'fit in' with normal or SEN Fear of social exclusions by association Needs not understood by those who should know
Social comparison		
Fitting in/standing out		
Socially excluded by physical removal		

Interview 13 List of emergent themes

The everyday challenge - being “a little bit different”

- 26) Everyday challenge
- 26) Extra effort
- 26) variable impact
- 26) Extra time and effort to achieve acceptable outcome
- 30) Extra time and effort to achieve the same
- 30) Making mistakes (writing)
- 30) Cumulative impact of small errors
- 30) Extra time and effort to achieve the same
- 32) An acceptable standard – good enough
- 42) Writing is an additional pressure not experienced by peers
- 42) Writing as a barrier to written expression
- 44) Potential impact of poor handwriting on exam results
- 44) Disadvantaged by poor presentation
- 46) Variable performance – handwriting
- 52) Variable impact
- 54) Variable impact
- 68) Concentration and attention
- 72) Attention & concentration – hidden impact on learning
- 74) Writing as an additional pressure (compared to peers)
- 74) More things to worry about in exams
- 124) “A little bit different”
- 182) Variable impact at home
- 188) Relationship with sister
- 188) Relationship with parents

Fitting in and standing out (social impact)

- 28) Social comparison – boys aren’t that good at drawing
- 28) Fitting in – not so different
- 44) Standing out – exam arrangements
- 44) Having to justify different arrangements to peers
- 44) Fitting in or standing out
- 44) Tension between being conspicuous and benefitting from strategies
- 46) Fitting in or standing out? Use of laptop in lessons
- 46) Desire for social conformity and acceptance
- 46) Role as discloser
- 56) Social comparison with less able peers
- 56) Fitting in or standing out
- 56) Socially excluded by physical removal from peers
- 80) Rejection of ‘visible’ support (LSA)
- 122) Awareness of extended family
- 122) Limited impact of dyspraxia on family relationships
- 122) Disclosure of diagnosis to explain visible signs
- 124) Visibility of dyspraxia
- 124) Valuing acceptance and understanding by extended family
- 126) Selective disclosure
- 126) Fear of disclosure leading to being treated differently
- 126) Desire to fit in (Cadets)
- 126) Timing of disclosure
- 126) Anticipating the reaction of others to disclosure

- 128) Lack of awareness (Cadet leaders)
- 128) Lack of understanding affects decision to disclose
- 128) Uncertainty – will disclosure be of benefit?
- 130) Acceptance linked to length of relationship with peers
- 130) Acceptance linked to familiarity with other disabilities
- 130) Familiarity with other disabilities increases acceptance
- 130) Selective disclosure – “need to know” basis
- 134) Laptop as a visible sign of dyspraxia
- 134) Social impact (peers and laptop)
- 136) Humour as coping strategy
- 138) Coping with comments
- 146) Social confidence
- 148) Socially confident
- 150) Disclosure to close friends
- 152) Typical teenager – social activities
- 156) Leisure interest in sport
- 180) Leisure interests – cinema

Feeling understood and supported (Emotional impact)

- 18) Lack of understanding affects experience (teacher)
- 20) Lack of understanding reinforces negative self-concept
- 22) Lack of respect for teacher
- 22) Negative response reinforces negative self-concept
- 22) Lack of respect for teacher’s ignorance
- 24) Feeling let down by teacher
- 24) Ineffective process for providing support
- 24) Lack of respect for ignorant teacher
- 38) Feeling understood and supported (teacher)
- 46) Explanation leads to acceptance & understanding
- 100) Positive role models
- 100) Inspired to believe anything is possible
- 100) Daniel Radcliffe as a role model
- 100) Daniel Radcliffe as a catalyst for optimism about the future
- 100) Rethinking possibilities for the future
- 102) Feeling a connection with Daniel Radcliffe (age and disability)
- 102) Legitimizing dyspraxia
- 102) Someone to speak out for me – raising awareness
- 104) Awareness leads to acceptance by others
- 104) Public awareness demystifies the condition
- 106) Mystery of dyspraxia
- 106) Comparing different disabilities
- 106) Dyspraxia as a low-profile condition
- 106) Optimism for increased awareness and understanding
- 108) Social responsibility to raise awareness
- 108) Sharing experiences helps to reduce isolation and misunderstanding about dyspraxia
- 112) Mystery of dyspraxia – terminology
- 118) Terminology is confusing
- 126) Lack of confidence
- 166) Attitude of adults influences disclosure decisions
- 166) Adult experience of additional needs inspires confidence

Interview 13 List of emergent themes

- 166) feeling accepted and understood – Cricket for Change
- 166) Awareness and understanding encourages participation (cricket)
- 172) Fear of failure inhibits participation
- 172) Fear of difficulties being exposed limits participation
- 172) Lacking confidence to try new things
- 174) Negative self-image

Right help, right time

- 38) Strategies are supportive (extra time, exam arrangements)
- 40) Right support, right time
- 40) Making choices – which support to take
- 40) Laptop as a removes writing barrier
- 40) Laptop reduces pressure
- 44) Choices and decisions – to take support or not?
- 50) Autonomy – making choices about support
- 50) Feeling in control -accepting or disregarding advice
- 54) Making choices (support)
- 56) My difference is different to their difference – need for differentiated support
- 56) Unhelpful help
- 58) Need for differentiated support
- 58) Right support at right time
- 60) Your difference is different to my difference
- 60) One size of support doesn't fit all
- 64) Feeling supported in exams
- 66) Managing stress of exams
- 76) Supports are a compensation not a privilege
- 76) Supports redress the balance
- 78) Usefulness of strategies depend on the context (right support right place)
- 80) Need for support tailored to needs
- 68) Parents as supports
- 120) Laptop as a compensation not a privilege
- 196) Disclosure as access to resources

Coping with dyspraxia over time

- 10) Autonomy and control (school subjects)
- 12) Sense of control (school subjects)
- 22) Rationalizing – use of future strategies
- 52) Increased performance expectations with age
- 52) Challenge of increased pace of work
- 64) Normal pressure of exams
- 82) Dyspraxia as a factor in making decisions about future college
- 82) Balancing potential opportunities (college) with familiarity and need for support
- 84) Optimism for the future
- 84) Future possibilities
- 86) Positive outlook for the future
- 88) Planning for the future
- 88) Thinking ahead
- 82) Future aspirations
- 92) Dyspraxic identity emerged over time

- 92) Delay before being labelled
- 94) Label made little difference
- 96) Awareness of disadvantages increases over time
- 96) Temporal – unaware of being different
- 96) Anticipates impact of difficulties in the future
- 98) Visible signs of dyspraxia – awareness of others
- 98) With time and effort can overcome the challenges
- 98) Acceptance – dyspraxia can be managed
- 98) Managing the condition, not curing it
- 104) Acceptance – not ashamed
- 104) Living with dyspraxia
- 120) Having dyspraxia provides the opportunity to help others by raising awareness
- 122) Parental role in identifying dyspraxia
- 142) Acceptance of own difference
- 142) Not that different
- 154) Coping with additional health issues
- 182) Relationship with parents – stressful
- 186) Expectations of performance vary with age – Airfix
- 192) Parental role as guides/counsellors
- 190) Strategies to cope with emotional pressure
- 194) Parents as supports
- 194) Desire to be independent
- 196) Self-belief in abilities
- 196) Sense of agency and control
- 196) Disclosure as access to emotional and social support

Extract from Interview 13 emergent theme table (illustrating one theme)

Higher order themes	Subthemes	Illustrative example (paragraph number)
The everyday challenge	Managing multiple issues	I've got asthma and everything so there is a lot more challenge, not really challenging but I've obviously got to watch how far I push myself (154)
	Changing environment & expectations over time	In the practical subjects which I did it was a lot more of an issue but now obviously I've dropped them it's not really (54)
		I felt it (Year 7) was a lot more kind of like relaxed and stuff and like at a slower pace (52)
		In year 7,8,and 9 it was a bit more kind of, like it was like a bit, it's not as serious obviously as GCSE 'cause these are like really important now (52)
		My Dad used to buy me all these like Airfix kits of like planes and stuff... I sometimes found it a bit hard to like gluing all the parts together and painting stuff... but I haven't really done anything like that for like two, three years now (180)
		As I'm getting older I'm realising more how it's gonna affect me and the exams and then like obviously then like simple things like tying laces or doing a tie, I'm just going to find a lot harder than someone else (96)
	<i>"It doesn't affect me all the time"</i>	It affects me if I'm doing something kind of like constructive or something like that, but it doesn't affect me necessarily all the time (182)
		I'm walking home from school in the snow and stuff, it's quite difficult to keep balance. I mean every, I know everyone will find it difficult but like I just, I, I can't like, I just don't find it that easy. (30)
		I can read my own writing and most of the teachers I think can. It's just the fact that sometimes it's neater than other times (46)
	<i>"It takes more effort and practice"</i>	I think it takes more effort and practice to get stuff like not perfect but do stuff like to a standard that's OK (32)
		There are some things which other people just get like that (clicks fingers), like tying my shoelace or something like that, which took me a lot longer to grasp (26)
		Things which some people find easier, like drawing a square or 3D shapes, I just find it like so hard (26)
	<i>"My mind just wanders onto something different"</i>	I find it really hard to concentrate, you know, in stuff like maths (68)
		I just like start un-focussing and start focusing on other things or things about other things. My mind just wanders onto something different (72)

Spring 2012: Group themes

Understanding and accepting myself

- The mystery of dyspraxia (14)
- Awareness and understanding of dyspraxia (13)
- Understanding dyspraxia (12)
- Dyspraxia as 'a bit of a problem' (14)
- Feeling and looking stupid (16)

Needing a bit of help

- Needing a little bit of help (16)
- The support that I need (15)
- Challenge of accessing appropriate support (14)
- Support and understanding (13)
- Practical solutions (12)

Standing out and fitting in

- Acceptance (15)
- Social impact (15)
- Social impact (14)
- Family relations (16)
- Standing out and fitting in (13)
- Feeling and looking stupid (16)

Emotional well-being

- Growing confidence and self-esteem (16)
- Confident and secure (15)
- Emotional impact (14)
- Emotional well-being (13)
- Managing stress and emotions (12)

The everyday challenge

- Coping with the everyday challenge (16)
- The everyday challenge (15)
- The everyday challenge (13)
- Changing environment and expectations over time (13)
- Being in Year 11 (15)
- It doesn't affect me all the time (13)
- It affects me 'certain times' (16)
- Coordination and handwriting (14)
- My organisation isn't great at all (15)
- Impact of poor organisation (16)
- My mind just wanders onto something different (13)
- Concentration and learning styles (14)
- Lacking patience (16)
- Managing multiple issues (13)

Appendix G Publications

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Appendix H: Academic Posters

Presented at the College of Occupational Therapists Annual Conference, Brighton 2010

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Presented at the Developmental Coordination Disorder Conference, York 2010

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Presented at the Research Symposium Faculty of Health & Life Sciences, Coventry

University 2011

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Presented at the Research Symposium Faculty of Health & Life Sciences, Coventry

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Presented at the European Academy of Childhood Disability Conference, Newcastle 2013

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Appendix I: Conference presentation abstracts

Oral presentation to the College of Occupational Therapists Specialist Section Children, Young People & Families, Bristol 2011



Full name of all presenters	Sally Payne
Contact email of main presenter	Sally.payne@heartofengland.nhs.uk
Organisation	Heart of England Foundation NHS Trust
Presentation format - please select a format and delete the other two	Research/ paper
Category of submission	1). Innovation in Practice
Description – 250 words maximum including 3 outcomes of the presentation which will be of direct benefit to the audience.	<p>Dyspraxia, or developmental coordination disorder (DCD) is a life-long condition that can affect many aspects of a person's daily life. However, research into the condition has tended to focus on younger children and much less is known about what happens to people with dyspraxia during adolescence. (The term dyspraxia is used as according to a recent survey this term is preferred by teenagers/adults to describe their condition).</p> <p>This paper will describe the findings of a study to explore how life is experienced by teenagers with dyspraxia aged 13 years from their own contemporaneous perspective. A qualitative, interpretative phenomenological analysis (IPA) framework was used to analyse 6 individual interviews with teenagers with a primary diagnosis of dyspraxia or DCD.</p> <p>This paper will present the major themes that illustrate the experience of living with dyspraxia aged 13 years. It is hoped that these findings will help organizations (both statutory and voluntary) to develop services and resources to support teenagers with dyspraxia. The findings will also be of interest to researchers who wish to develop studies that will better reflect the experiences of teenagers with dyspraxia in the future.</p> <p>By the end of this presentation the audience will:</p> <ul style="list-style-type: none"> • develop their understanding of what matters to teenagers living with dyspraxia • Consider how occupational therapy services can better meet the needs of teenagers with dyspraxia • Have the opportunity to learn about this relatively new research approach and its relevance to occupational therapy
Ethical approval body	Coventry University Ethical Approval 2009
Submission Code (admin use only)	

***“I don’t know if I have it or not”* How teenagers with DCD make sense of their diagnosis
– an interpretative phenomenological analysis**

Authors:

Sally Payne – Head Paediatric Occupational Therapist, Heart of England Foundation
NHS Trust, PhD Student, Coventry University and Chair, Dyspraxia
Foundation

Gillian Ward - Principle Lecturer, Coventry University

Andy Turner – Senior Research Fellow, Coventry University

Clare Taylor - Senior Lecturer, Bournemouth University

Chris Bark - Subject Librarian, Coventry University

Introduction

Although there is a growing body of research examining what happens to individuals with Developmental Coordination Disorder (DCD) as they grow older, there is very little contemporaneous research from a teenage perspective. The term “dyspraxia” is sometimes preferred by people living with this condition. This paper describes one of the superordinate themes arising from an analysis of a study to explore the experience of teenagers living with DCD/dyspraxia – the struggle to make sense of their diagnosis.

Method

Semi-structured interviews were conducted with six young people with DCD/dyspraxia (as previously diagnosed by a paediatrician) aged 13 years. Data were analysed using interpretative phenomenological analysis.

Findings

For many participants there was a delay between the diagnosis of DCD/dyspraxia and its subsequent disclosure to themselves, so that awareness of their diagnosis emerged over time. Participants experienced a sense of confusion and uncertainty about the diagnosis which was often confounded by variations in its presentation and by the invisibility of others with the condition to whom participants could compare themselves. This uncertainty made it difficult for participants to explain their condition to their peers and in some cases this heightened their sense of social isolation, impacting on emotional and social well-being. Attempts by some participants to find out more about DCD/dyspraxia had not always been successful.

Conclusion

For these participants, DCD/dyspraxia remained a mysterious and confusing condition and, with the exception of one individual whose associated speech difficulties were identified aged two years, DCD/dyspraxia was not fully integrated into their sense of self-identity.

Workshop Questions

- How can we ensure that the young person’s perspective is included in future research into DCD?
- How can practitioners help teenagers to better understand and manage their condition?
- When is the right time to tell a young person that they have DCD?

Key messages for practice

- Teenagers need access to clear information about DCD so they can better understand their condition and articulate this to others when appropriate
- Parents/carers need help to weigh up the benefits and disadvantages of discussing their child's diagnosis with them.
- Practitioners should consider ways to reduce the sense of isolation among teenagers with DCD for example, by using social media and other innovative technologies.

Email contact of first author

teenresearch@dyspraxiafoundation.org.uk

User involvement in a study to find out what matters to teenagers living with dyspraxia

Presenters

Sally Payne, Occupational Therapist, Heart of England Foundation NHS Trust and PhD student, Coventry University

Ben Smith, Olivia Hull and Emily Woollard, experts through experience

Biographies

Sally has been an occupational therapist for over 20 years and a Trustee of the Dyspraxia Foundation for almost 10 years. She has a particular interest in dyspraxia and was inspired to carry out research to explore the experiences of teenagers to address a lack of knowledge in this area.

Ben, Olivia and Emily are all young adults (either working or students) who met Sally through her work as an occupational therapist while they were still at school.

The project

The aim of this project was to find out how life is experienced by teenagers who have dyspraxia, a disorder of the organisation of movement, thought, perception and sometimes speech. Previous research has focused on younger children and although there is evidence that difficulties associated with dyspraxia often continue into adulthood, very little is known about how dyspraxia affects people during their teenage years. The study involved a series of interviews carried out by the researcher with a group of teenagers with dyspraxia over the course of two years using a research approach known as interpretative phenomenological analysis.

This presentation describes the involvement of a group of older teenagers/young adults with dyspraxia who acted as a “reference group” for the project. Their role was to give advice about making the participants felt safe enough to share their stories; suggesting questions that could be asked; and adding an “insider’s perspective” to help the researcher analyse the interviews. This presentation will use a combination of presentation, discussion and film to illustrate the challenges and benefits of involving users in a qualitative research project from the perspective of the researcher and reference group members, and to describe how the project will benefit teenagers with dyspraxia.

Appendix J: Newsletters

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College of Occupational Therapists Research and Development Bulletin, November 2013

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Appendix K; Ethical Approval

Coventry University
Priory Street
Coventry CV1 5FB
Telephone 024 7688 7688
Vice-Chancellor's Office



Sarah Payne
HLS PhD Student

Dear Sarah Payne,

Medium Risk Ethical Approval for PhD Thesis – ‘Teenagers Experience of Dyspraxia’

I grant retrospective medium risk ethical approval for the above thesis on the basis that at the time the your research started in 2009 the policies and norms now expected as part of CU-Online Ethics system are not as evolved as they are today.

The decision to sign the study off as ‘low risk’ was made at the PRP in September 2009 which was chaired by Chris Carpenter and attended by Clare Taylor (Director of Studies) and Louise Connelley (expert) who are all experienced qualitative researchers. The decision to consider the study to be low risk was made by those present at the PRP for the following reasons:

Risk to participants

- The study did not involve patients/service users therefore NHS ethical approval was not required (this was confirmed by a member of the local NHS Research Ethics Committee with whom I work)
- The study did not involve invasive procedures and a maximum of 3 interviews would be held over a 3 year period i.e. limited participant involvement
- Data collection was by semi-structured interview. Interviews were participant-led and questions did not focus on sensitive issues. Participants therefore had the option to raise or not raise issues as they wished.

Risk to researcher

- Recruitment was via a national support group (of which I am a member) whose medical panel reviewed the study and who promoted the study via membership communications (newsletters etc)
- Participants and their parents are known to the support group who provide appropriate and on-going support to all members
- The panel recognised that I am an experienced therapist who carries out interviews on a daily basis as part of my clinical role. They (and I) felt confident that I had the skills and experience to cope with any sensitive issues that might be raised by participants during interview.
- Interviews were held at participants’ homes with parents nearby. The panel felt that this was an appropriate level of supervision, given the qualitative nature of the study and the age of participants involved.

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Appendix K; Ethical Approval

Informed consent of the participant


- Potential participants were invited to volunteer for the study by responding to advertisements shared by the support group.
- Both participants and their parents gave their consent for involvement
- Participants were deemed to have the capacity to consent to participation.

Gatekeeper risk

- The panel considered that it was more appropriate for participants to be interviewed in their own homes rather than bringing them into an unfamiliar university setting. Being interviewed on familiar territory was likely to be less intimidating for participants, and reflects clinical practice in which I often meet teenagers and their parents at home as part of the therapeutic process.

The External Examiners and I are all satisfied that the research was carried out in an ethical manner.

Yours sincerely



Prof Ian M Marshall

Deputy Vice Chancellor (Academic)

